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REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

HEARING

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

FIRST SESSION

ON

EXAMINING PROPOSED LEGISLATION TO REAUTHORIZE THE PROGRAMS OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

APRIL 8, 1987

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REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

WEDNESDAY, APRIL 8, 1987

U.S. SENATE,
SUBCOMMITTEE ON THE HANDICAPPED,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The Committee met, pursuant to notice, at 2:35 p.m., in Room SD-430, Dirksen Senate Office Building, Senator Tom Harkin (chairman of the subcommittee) presiding.

Present: Senators Harkin, Thurmond, Weicker, Stafford, and Simon.

OPENING STATEMENT OF SENATOR HARKIN

Senator HARKIN. The Subcommittee on the Handicapped of the Labor and Human Resources Committee will come to order.

Today, the Subcommittee on the Handicapped meets to review programs authorized under the Developmental Disabilities Assistance and Bill of Rights Act which expires at the end of this fiscal year. The Act has four components—first, the basic State grant program, secondly, the protection and advocacy system; third, the university-affiliated programs, and fourth, the special projects.

The State grant program provides payments to States to plan for and to conduct activities which will increase and support the independence, productivity and integration into the community of persons with developmental disabilities. The Protection and Advocacy agencies protect and advocate for the rights of such persons to legal, administrative and other appropriate remedies. University-Affiliated Programs provide interdisciplinary training for professionals in the field of developmental disabilities and conduct numerous service demonstration programs. And the fourth, the Special Projects grants, fund national significant demonstration projects and technical assistance projects. The four components of the Act are funded at a combined level of $83.7 million this year.

While the programs authorized under this Act are small compared to other legislation under the Subcommittee's jurisdiction, they have had significant impact on the lives of many persons with developmental disabilities.

Only a generation ago, persons with developmental disabilities and their families had limited options, consisting primarily of institutionalization. The Developmental Disabilities Act has been a major impetus for the creation of the many and varied programs now available that allow individuals with developmental disabilities to assume socially valued roles, to live in communities, to participate in competitive employment, and in some cases, to leave the SSI rolls and develop greater self-respect and dignity.

We have several witnesses with us today who will review some of the accomplishments of the Act and help us to determine, what if, any additions, deletions, or modifications should be made to the Act.

First, the Honorable Strom Thurmond, the distinguished Senator from South Carolina, will describe the National Information System of Health-Related Services, and then describe the bill he has introduced, S. 926, to amend the Developmental Disabilities Act to include authorization for this system.

Second, we will hear from Dr. Jean Elder, the former Commissioner of the Administration on Developmental Disabilities of Health and Human Services and currently the Acting Assistant Secretary for the Office of Human Development Services.

The next panel includes consumers. Lynn Wasik and Todd Kilroy will share with us the positive impact that the Act has had on their lives and the lives of others. Dolores Everitt will share with us her concerns about issues yet to be adequately addressed, such as what happens to an adult with a developmental disability when his or her parents become too old to provide care, or when his or her parents die?

The final panel consists of three witnesses. Dr. Healy, from the University of Iowa, will provide us with an historic perspective about the Act and society's changing attitudes regarding persons with developmental disabilities. Judy Hoyt will describe for us the breadth of the population covered by this term, "developmental disabilities".

And the final witness, Dr. Elizabeth Boggs, a lifelong advocate for persons with developmental disabilities, will present the recommendations of the Consortium for Citizens with Developmental Disabilities.

I now want to recognize the distinguished Senator from Vermont for any opening statement he may have.

OPENING STATEMENT OF SENATOR STAFFORD

Senator STAFFORD. Thank you, Mr. Chairman.

I do wish to congratulate you for having this important oversight hearing in order to receive input for the reauthorization of the Developmental Disabilities and Bill of Rights Act. This legislation has been in existence for over 20 years, and during that time it has been substantially amended and changed.

And as an aside, I will say, Mr. Chairman, that I have served on this Subcommittee and have considered it a privilege and a labor of love to do so throughout the last 16, going now on 17 years, first under Jennings Randolph, who was so able a Senator in his time and Chairman of this Subcommittee, and I look forward now to serving under your leadership here.

In 1984, Congress made the following changes in this Act. First, it incorporated the words, "independence, productivity and integration" throughout the act; secondly, added employment-related activities as a priority as well as a definition of supported employment; third, expanded the definition of university-affiliated facility to add a technical assistance capability; and fourthly, added a requirement for an annual report to Congress regarding the activities and accomplishments of this program, and fifthly, specified that 65 percent of the State Council's funds be used for service activities.

The changes made by the '84 Amendments have assisted my own State of Vermont in providing services to individuals with developmental disabilities, especially in the area of employment-related services. These changes are a reflection of the continuous technological improvements and the innovative programming occurring in our society.

So I look forward, Mr. Chairman, to hearing from the witnesses today, with their views on the amendments made in 1984 as well as their suggestions for improvements for the Developmental Disabilities Act.

Thank you.

Senator HARKIN. Thank you very much, Senator Stafford.

Let me just thank you for your many years of service to this Subcommittee and to the people this Subcommittee seeks to serve. I can just assure you that this new Chairman and this new area will be looking to you for guidance, consultation, and help and support to help continue to meet these challenges. I know your staff has been very capable and very helpful, and I appreciate it very much.

Senator STAFFORD. We will be glad to work with you.

Senator HARKIN. Thank you.

Senator Simon, do you have a statement?

OPENING STATEMENT OF SENATOR SIMON

Senator SIMON. Mr. Chairman, I first want to welcome you to the chairmanship of the Subcommittee on the Handicapped. Having worked with you in the House and seen your dedication to human rights in all its forms, I know you are a champion for the programs in the jurisdiction of this subcommittee.

During the entire time I've been in Congress, I have been a member of the subcommittee, first in the House and then in the Senate, that looks out for the concerns of people with disabilities. Although our attention is frequently pulled in many directions and we can't spend as much time as we would like on any one issue, there is no area of greater concern to me than that represented in this subcommittee. I want to pledge my support to you, Mr. Chairman, in the efforts you make to carry on the tradition of advocacy of this subcommittee—the tradition of members such as Senator Jennings Randolph, and our colleagues Bob Stafford and Lowell Weicker.

The statute we are looking at in these hearings is an illustration of legislation that can result from this subcommittee's awareness and concern about a population group that clearly deserves our attention. The intolerable conditions of institutions for the mentally handicapped, the lack of planning for services for persons with developmental disabilities, and the lack of advocacy for their rights drew a response in legislation in the Developmental Disabilities Act. The law has been changed over the years in an effort to make it more inclusive and to more adequately meet the needs of those who are looking for an opportunity to contribute and be a part of the community life.

I will look to your guidance, Mr. Chairman, and the advice of those such as the witnesses today, in supporting further changes that may be warranted in this law. I look forward to working with you on a reauthorization bill that continues to move us forward in helping those with developmental disabilities to realize their full potential.

Senator **Harkin**. We will now hear from Senator Weicker.

OPENING STATEMENT OF SENATOR WEICKER

Senator **Weicker**. Today the subcommittee meets to review programs authorized under the Developmental Disabilities Assistance and Bill of Rights Act.

Although small in comparison to other Federal programs for disabled people, funds from the developmental disabilities program have a multiplier effect, stimulating funding from States and other sources to promote the goals of independence, productivity, and integration of disabled into the workplace and the community.

These goals were set forth in the 1984 amendments to the Developmental Disabilities Act, and laid the foundation for the progressive changes made last year to both the rehabilitation and education of the handicapped acts.

Certainly, the testimony we will receive today will be invaluable to us as we develop a reauthorization bill which ensures that the DD Act remains on the "cutting edge," if you will, of legislative initiatives to improve the qulaity of life for our Nation's handicapped individuals.

I look forward to hearing today from our witnesses regarding the progress we have made towards achieving these goals through programs authorized under the DD Act, as well as what additional challenges lie ahead as we further refine this legislation.

Finally, I'd like to say to our new chairman, Senator Harkin, how much I look forward to working with him, not only on this bill, but on all matters the Handicapped Subcommittee will be considering during the 100th Congress.

Senator **Harkin**. The prepared statements of Senators Kennedy, Hatch, and Cochran will be inserted in the record at this point.

[The statements referred to follow:]

STATEMENT OF SENATOR EDWARD M. KENNEDY AT THE HANDICAPPED SUBCOMMITTEE HEARING ON THE REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ACT.

I WANT TO COMMEND THE CHAIRMAN OF THE SUBCOMMITTEE, SENATOR TOM HARKIN, FOR HIS LEADERSHIP IN PURSUING EXPANDED OPPORTUNITIES FOR HANDICAPPED AMERICANS. HIS CONCERN AND COMMITMENT TO OUR NATION'S DEVELOPMENTALLY DISABLED INDIVIDUALS ARE IMPORTANT TO THE NEEDS OF MILLIONS OF AMERICANS.

OUR HEARING TODAY IS ANOTHER STEP ON THE MARCH TO EQUALITY THAT BEGAN IN 1963 WHEN PRESIDENT KENNEDY INITIATED THE FIRST MENTAL RETARDATION LEGISLATION. HE SAID THEN THAT THE NON-SYSTEM OF MENTAL HEALTH CARE "HAS BEEN TOLERATED TOO LONG. IT HAS TROUBLED OUR NATIONAL CONSCIENCE, BUT ONLY AS A PROBLEM UNPLEASANT TO MENTION, EASY TO POSTPONE AND DESPAIRING OF SOLUTION."

IN THE LAST QUARTER CENTURY, WE HAVE MADE GREAT PROGRESS. MENTAL HEALTH CARE INCREASINGLY HAS SHIFTED FROM VAST INSTITUTIONS WHERE PEOPLE WERE CONFINED--TO COMMUNITY SETTING

WHERE THE FUNDAMENTAL GOAL IS TO PERMIT EVERY INDIVIDUAL TO ACHIEVE MAXIMUM DEVELOPMENT OF HIS OR HER TALENT AND POTENTIAL.

IN THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT, WE TOOK A MAJOR STEP TO GIVE SUBSTANCE TO THE NATIONAL POLICY OF DEINSTITUTIONALIZATION. WE WERE DETERMINED TO ENACT A FEDERAL-STATE PARTNERSHIP AIMED AT COMPREHENSIVE SERVICE TO THE DEVELOPMENTALLY DISABLED CITIZENS IN OUR NATION.

IN THE ENSUING YEARS, ADVANCED TECHNOLOGY, A MORE SOPHISTICATED WAY OF ADDRESSING THE NEEDS OF OUR NATION'S DEVELOPMENTALLY DISABLED CITIZENS, AND EDUCATIONAL EFFORTS AIMED AT MAINSTREAMING THESE CITIZENS HAS HELPED MAKE THE LIVES OF THESE INDIVIDUALS MORE PRODUCTIVE AND FULFILLING. BUT JUST AS IMPORTANTLY, SOCIETY AS A WHOLE HAS BENEFITTED TREMENDOUSLY FROM THE INSIGHTS AND CONTRIBUTIONS THESE INDIVIDUALS HAVE MADE TO OUR NATION.

ONE POINT OF CONCERN TO ME IS THE LACK OF SERVICES FOR THE AGING MENTALLY RETARDED. WHEN MOST OF THE RETARDED ELDERLY WERE GROWING UP THERE WERE NO COMMUNITY-BASED SERVICES AVAILABLE. FOR THE MOST PART, THESE PEOPLE WERE SENT TO STATE INSTITUTIONS AND HAVE BEEN, FOR THE MOST PART, DEINSTITUTIONALIZED.

THE RETARDED ELDERLY WHO ARE NOW LIVING AT HOME ARE LIVING LONG ENOUGH TO SEE THEIR OWN PARENTS BECOME DISABLED OR DIE. THESE INDIVIDUALS NEED SPECIAL ASSISTANCE RANGING FROM RECREATION TO ADULT EDUCATION TO A SOCIAL SUPPORT NETWORK.

I URGE MY COLLEAGUES ON THE SUBCOMMITTEE TO ADDRESS THE NEEDS OF OUR NATION'S AGING MENTALLY RETARDED POPULATION.

I WOULD LIKE TO THANK OUR WITNESSES FOR PROVIDING THE SUBCOMMITTEE WITH THEIR TESTIMONY. YOUR COMMITMENT AND CONCERN TO IMPROVING THE LIVES OF DISABLED AMERICANS IS COMMENDABLE, AND I AM SURE YOUR INSIGHTS WILL PROVIDE THE SUBCOMMITTEE WITH HELPFUL INFORMATION.

STATEMENT OF SENATOR ORRIN G. HATCH

HEARING ON REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ACT

APRIL 8, 1987

I AM PLEASED TO BE ABLE TO PARTICIPATE IN TODAY'S HEARING TO REVIEW THE DEVELOPMENTAL DISABILITIES PROGRAM. AS THE FIRST STEP IN PREPARATION FOR REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES AND BILL OF RIGHTS ACT, IT IS IMPORTANT THAT WE HAVE THE OPPORTUNITY TO HIGHLIGHT PROGRAM ACCOMPLISHMENTS AS WELL AS IDENTIFY AREAS FOR IMPROVING THE PROVISION OF SERVICES.

SINCE 1978 WHEN I BEGAN MY CAREER IN CONGRESS AS A MEMBER OF THE SUBCOMMITTEE ON THE HANDICAPPED, I HAVE SEEN TREMENDOUS GROWTH AND PROGRESS IN THE FIELD OF DEVELOPMENTAL DISABILITIES. ORGINALLY PASSED TO COORDINATE AND PROVIDE NECESSARY SERVICES TO THE MORE SEVERELY HANDICAPPED PERSONS OF OUR NATION, THE DEVELOPMENTAL DISABILITIES ACT HAS HELPED TO ELIMINATE GAPS IN SERVICES ESPECIALLY IN RURAL AND PREVIOUSLY UNDERSERVED REGIONS.

THE DEVELOPMENTAL DISABILITIES PROGRAM IS DIVIDED INTO FOUR MAJOR COMPONENTS CONSISTING OF STATE GRANTS, PROTECTION AND advocacy, Special projects and university affiliated facilities. Each has a major function in the provision of services to our 3.9 million developmentally disabled Americans, 27,000 of whom reside in my state of Utah. I am pleased that the witnesses here today will further clarify the tremendous role the Developmental Disabilities program has played in helping persons with developmental disabilities become more independent and self-sufficient individuals.

As the former Chairman of the Labor and Human Resources Committee, I was an active participant in the drafting of the 1984 amendments to the Act. Our legislation emphasized the need for increasing employment opportunities. In the past few years, we have now seen more than 87,000 persons with developmental disabilities find jobs in the private sector. Instead of relying on public assistance, these handicapped employees have become a valuable asset to their communities. What a tremendous tribute to the efforts of the Administration of Developmental Disabilities.

As demonstrated by my previous legislative activities, I support the important role the Federal government has played in assisting the States with planning, coordinating, monitoring and in providing research, training and necessary services for this special population. Congress now has the

OPPORTUNITY TO FURTHER REFINE AND FINE TUNE THIS ACT MAKING IT EVEN MORE RESPONSIVE IN ADDRESSING THE NEEDS OF OUR 3.9 MILLION DEVELOPMENTALLY DISABLED CITIZENS. I COMMEND SENATOR HARKIN AND THE OTHER MEMBERS OF THE SUBCOMMITTEE ON THE HANDICAPPED FOR MAKING THE REAUTHOIZATION OF THE DEVELOPMENTAL DISABILITIES ACT A PRIORITY ISSUE. I HOPE THAT WE CAN EXPEDITIOUSLY MOVE ITS PASSAGE THROUGH CONGRESS.

Thad Cochran

STATEMENT FOR THE RECORD
SENATOR THAD COCHRAN
SUBCOMMITTEE ON THE HANDICAPPED
APRIL 8, 1987

"REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ACT"

MR. CHAIRMAN, I AM PLEASED TO BE A MEMBER OF THIS PANEL, AND COMMEND YOU FOR HOLDING THIS HEARING TODAY.

IN THE LAST 20 YEARS, WE HAVE WITNESSED A TREMENDOUS CHANGE IN THE PHILOSOPHY AND METHOD OF CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES. WE HAVE MOVED AWAY FROM INSTITUTIONAL CARE TOWARD SMALLER COMMUNITY-ORIENTED FACILITIES THAT, MOST LIKELY, ENHANCE THE FULL DEVELOPMENT OF THESE INDIVIDUALS' HUMAN POTENTIAL.

THE FEDERAL GOVERNMENT'S COMMITMENT TO ASSIST IN THE PROVISION OF LONG TERM, STABLE AND QUALITY CARE FOR THOSE WHO SUFFER FROM SEVERE, CHRONIC, PHYSICAL OR MENTAL DISABILITY IS DEMONSTRATED IN THE VARIETY OF HEALTH, EDUCATION, HUMAN DEVELOPMENT AND REHABILITATION PROGRAMS CURRENTLY FUNDED WITH FEDERAL DOLLARS.

WE NEED TO, AND WANT TO, EXPAND AND REFINE THESE SERVICES. THERE IS A CONTINUING PROLIFERATION OF NEW THINKING IN THE DEVELOPMENTAL DISABILITIES FIELD. IT IS IMPORTANT THAT THIS SUBCOMMITTEE MOVE FORWARD TO INCORPORATE THESE INNOVATIONS INTO THE SYSTEM OF SERVICES PROVIDED BY THE DEVELOPMENTAL DISABLITIES ACT.

I WANT TO THANK THE WITNESSES FOR BEING HERE TODAY. I AM SURE THAT THEIR TESTIMONY WILL SERVE AS INSPIRATION AS WELL AS AN EDUCATIONAL TOOL FOR US AS WE MOVE INTO THE REAUTHORIZATION PROCESS.

THANK YOU MR. CHAIRMAN.

Senator Harkin. Now we would like to recognize our first witness, the Honorable Strom Thurmond, the distinguished Senator from the State of South Carolina, regarding S. 926, the National Information System for Health-Related Services Act of 1987. Senator Thurmond, we are honored by your presence here today.

STATEMENT OF HON. STROM THURMOND, A U.S. SENATOR FROM THE STATE OF SOUTH CAROLINA

Senator Thurmond. Mr. Chairman, thank you for the opportunity to appear before this Subcommittee and to speak about a matter I feel would be of great benefit to the disabled and chronically ill children of this Nation.

Yesterday, I introduced legislation to authorize the establishment of a National Information System for Health-Related Services through the Department of Health and Human Services.

The system envisioned by this measure would involve a national computer-based information and referral service that provides information regarding specialized services available to developmentally disabled and chronically ill children. Contained in the computer's databank would be a wide range of information and services available from State agencies, hospitals, private associations, voluntary organizations, parent support groups, and more.

By calling a free access "1–800" number, anyone could find the organization providing the specialized service they need within that State. If the service is not offered in that State, the computer would expand its search into neighboring States, and if necessary throughout the country. A trained counselor would work with an individual to determine specific needs and using the computer to identify the closest agency or organization capable of meeting those specific needs.

Mr. Chairman, establishment and implementation of a centralized National Information System offers a cost-effective partial solution to a variety of the current concerns of parents of handicapped children and professionals in the health field. Foremost is the direct benefit the NIS provides by linking these children with the services they need. The ease with which this linkage can occur would result in reduced family frustration, reduced caseworker time required to search for client services, and reduced cost to the family and professional who would have spent valuable time and money searching.

Similarly, in a period of dwindling resources and increasing health care costs, the National Information System can highlight and direct attention to community-based services and make maximum use of private, voluntary and public resources. In this way, the system can bring the public and private sectors closer together in achieving a common objective in human health services.

The system proposed here expands the geographic area of search for those services not commonly available in close vicinity, and extends the search across State lines to all resource areas. It also would bring into the medical profession a complete, up-to-date inventory of services available to the patient, by coordinating and facilitating service delivery.

Simplifying and unifying access to information about services will greatly increase awareness and knowledge of what exists, resulting in greater utilization of those services. This in turn could contribute toward preventing or minimizing child health problems. Most importantly, the National Information System provides families everywhere cost-free access to information that can make a vital difference in the care and lifestyle they can offer their chronically ill or disabled child.

Mr. Chairman, other benefits would be achieved through the analysis of agency data stored on the NIS and analysis of consumer requests. Simple comparisons between the two can identify gaps in service delivery from region to region. Routine follow-up of people referred can also provide deeper insight into the quality, quantity and adequacy of various service programs.

The NIS therefore provides a unique tool for human services policymakers to use to improve resources available to the medical profession as they treat physical and mental health problems.

Mr. Chairman, there are several reasons why such a system should be set up as a national center rather than proceeding on a State-by-State basis.

First, with the technology of today, all the necessary information can be contained in one computer. It would be duplicative and unreasonably costly for each State to set up such a system on its own.

Second, the kind of specialized services available in each State vary greatly. In many cases, a parent of a handicapped child must travel to another State to obtain necessary specialized services. A national system would search, if necessary, beyond State borders to find the needed service provider, which a parent might otherwise never know about.

Third, as our society becomes more and more mobile, a national system is better able to respond. For example, we call upon members of the armed services to make a great sacrifice when they are frequently transferred. Those in the military, with a developmentally disabled or handicapped child, would have a great deal of anxiety relieved by being able to locate parent support groups and available agency assistance before they move. This could be done with one phone call to NIS.

Fourth, a national system, with a centralized collection of services available and requests made, can provide a unique tool for human service policymakers in better allocating Federal resources to the health field.

Mr. Chairman, with the technology available today, the National Information System is within our grasp. We have only to reach for it. As you work toward reauthorization of the Developmentally Disabled Act, I urge my colleagues on this Subcommittee to give careful consideration to the legislation I have introduced.

Mr. Chairman, I thank you again for the opportunity to appear before this Subcommittee and thank Senator Stafford for being here at this time, too.

Senator HARKIN. Thank you very much, Senator Thurmond, for that fine statement. I wondered if I might just ask you or counselor with you—there is a system, as I understand it, now in place in South Carolina that covers South Carolina that does this; is that right? Is there an 800 number you can call in South Carolina?

Senator THURMOND. I believe we do have some. Of course, it would not be adequate like this to take care of it.

Senator HARKIN. Is it working well? Have you had good success with it down there?

STAFF. Yes, sir. They currently have 20 States on-line, and the last I heard, they had up to 600 referrals a month, so they are doing a good job down there and were supported initially by some seed money from grants available in the Federal Government. But most of that has gone toward developing the system.

Senator HARKIN. The money for operating this comes out of what various programs now? I see the bill authorizes $750,000 per year.

Mr. SPONG. Yes, sir.

Senator HARKIN. Is that going to be enough to cover the operation of such a system?

Mr. SPONG. That is the figure suggested to us by the director of the system in South Carolina.

Senator HARKIN. To cover all 50 States?

Mr. SPONG. Yes, sir.

Senator THURMOND. They think that would be adequate—of course, they are not sure, but that is about as near as they could estimate it.

I cannot imagine a better service here for the whole Nation if this is done.

Senator HARKIN. Well, I like the concept. You are right, if you are going to just duplicate it from State to State, it is going to cost a heck of a lot more than if you have one centralized system. And as you say, the computers have the capacity now to put in all that database right now.

Well, it makes a lot of common sense to this Senator, and I can assure you this Subcommittee will give it very serious consideration and look at it. It just makes common sense.

Senator THURMOND. Thank you very much, Mr. Chairman, and thank you, Senator Stafford.

Senator HARKIN. Senator Stafford?

Senator STAFFORD. I have no questions of the very able and distinguished Senator from South Carolina. I appreciate his appearance here and his advice, and he is a member of this parent Committee, so we will continue to have his advice as we work on this legislation.

Senator THURMOND. Thank you very much.

Senator HARKIN. Senator Thurmond, thank you very much.

Our next witness will be Dr. Jean Elder, Assistant Secretary for the Office of Human Development Services-Designate, Department of Health and Human Services, accompanied by Robert E. Stovenour, Acting Commissioner of the Administration on Developmental Disabilities [ADD].

Dr. Elder, welcome to the Subcommittee. Without objection, your entire statement will be made a part of the record, and again please proceed as you so desire.

STATEMENT OF DR. JEAN K. ELDER, ASSISTANT SECRETARY-DESIGNATE, OFFICE OF HUMAN DEVELOPMENT SERVICES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY ROBERT E. STOVENOUR, ACTING COMMISSIONER FOR ADD

Dr. ELDER. Thank you very much.

I am delighted to be here, and also, I am delighted to see the good Senator from Vermont with us. I really welcome the opportunity to appear before this distinguished Subcommittee to discuss the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act.

I am especially pleased to be talking with you following the first national celebration of Developmental Disabilities Awareness Month as proclaimed by President Reagan on February 26, 1987.

When Congress set out to help developmentally disabled people, it was providing for one of the most vulnerable groups in this Nation. An individual is considered developmentally disabled when severe, chronic disabilities attributable to mental or physical impairments are manifested before the age of 22. Such disabilities can cause substantial limitations in at least three areas of major life activity and result in the need for services over an extended period of time.

We estimate that there are approximately 3.9 million persons with developmental disabilities in the United States, 2 million of whom are over the age of 18.

The Developmental Disabilities Act of 1984 established the following principles for the Developmental Disabilities Program: persons who are developmentally disabled should be able to exert control over their own lives; to engage in income-producing work, including competitive employment, or perform work which will contribute to a household or community; and to use community resources and live within that community.

The law reads: "It is the overall purpose of this Title to assist States to assure that persons with developmental disabilities receive the care, treatment, and other services necessary to enable them to achieve their maximum potential through increased independence, productivity, and integration into the community."

The legislation which we administer contains four major program components: the Basic State Grant program; the Protection and Advocacy grants; University-Affiliated Facilities, and Special Project grants.

At the Federal level, the Administration on Developmental Disabilities coordinates with various departmental and other agencies that provide funding for services needed by persons who are developmentally disabled. Two current examples of our coordination efforts are the Intra-Departmental Work Group on Policies Affecting Mentally Retarded and other Developmentally Disabled Persons and the Inter-Agency Committee on Developmental Disabilities.

In addition, the Administration on Developmental Disabilities has engaged the private sector in promoting self-sufficiency for persons with developmental disabilities through the employment initiative. President Reagan announced this initiative in November of 1983 as part of the National Decade of Disabled Persons. In the first two years of the initiative, approximately 87 thousand persons with developmental disabilities have been employed in private sector jobs. They will earn about $400 million in gross annual taxable wages, while the combined savings in public support costs and services will total nearly another $400 million.

This extraordinary accomplishment is due to the active support of corporations such as Radisson Hotels, Denny's Restaurants, the McDonald's Corporation, and many trade associations including the American Hospital Association and the National Restaurant Association.

The employment initiative has shown that given proper support services, persons with developmental disabilities can be employed at worksites where persons without disabilities are employed.

We support reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. The Administration's bill, entitled "Developmental Disabilities Assistance Amendments of 1987," was transmitted by the Secretary to Congress on March 9th, 1987, and was introduced as H.R. 1871. Our bill would extend authorization of the programs under the Act for three years, authorizing such sums as necessary for each of the fiscal years 1988, 1989, and 1990.

Second, our bill would add family support services as a priority service area in the Basic State Grant Program. This proposal would expand and provide crucial supportive services to families who care for their developmentally disabled family members within the home. Family support services are defined as services which strengthen the family's role as primary caregiver, prevent out-of-home placement, reunite families with members who have been placed out-of-home, and maintain family unity.

Family support services may include respite care, personal care, parent training and counseling, and other services which will support the well-being of families of persons with developmental disabilities.

Third, our bill would clarify the definition of "supported employment" to stress competitive employment of developmentally disabled individuals at worksites where individuals without disabilities are employed.

This proposal reaffirms our position that developmentally disabled individuals should participate fully in competitive employment and not be limited to sheltered workshops or other protected positions designed exclusively for persons who are developmentally disabled.

Finally, our bill would broaden the category of family representation on State Planning Councils to include relatives or guardians of formerly institutionalized persons with developmental disabilities. This provision would assist States in complying with the Planning Councils' composition requirement by expanding the available pool of parents or guardians eligible to serve on the Council.

In closing, I want to assure the Subcommittee that our policies have focused and will continue to focus on attaining the complementary goals of providing greater program authority at the State and local level, of supporting improved program efficiency, and of recognizing the needs, the potentials, and the accomplishments of persons with developmental disabilities.

I thank you, Mr. Chairman, and I would be happy to answer any questions you might have.

[The prepared statement of Dr. Elder follows:]

STATEMENT OF
JEAN K. ELDER, PH.D.
ASSISTANT SECRETARY FOR
OFFICE OF HUMAN DEVELOPMENT SERVICES-DESIGNATE
BEFORE THE
SUBCOMMITTEE ON THE HANDICAPPED
LABOR AND HUMAN RESOURCES COMMITTEE
UNITED STATES SENATE
APRIL 8, 1987

MR. CHAIRMAN, I WELCOME THE OPPORTUNITY TO APPEAR BEFORE THIS DISTINGUISHED SUBCOMMITTEE TO DISCUSS THE REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT. I AM ESPECIALLY PLEASED TO BE TALKING WITH THIS SUBCOMMITTEE FOLLOWING THE FIRST NATIONAL CELEBRATION OF DEVELOPMENTAL DISABILITIES AWARENESS MONTH AS PROCLAIMED BY PRESIDENT REAGAN ON FEBRUARY 26, 1987. OVER THIRTY STATES AND JURISDICTIONS HAVE ISSUED PROCLAMATIONS IN SUPPORT OF GREATER NATIONAL AWARENESS OF THE UNIQUE NEEDS, ACCOMPLISHMENTS AND POTENTIAL OF PERSONS WITH DEVELOPMENTAL DISABILITIES.

THE DEVELOPMENTALLY DISABLED POPULATION

WHEN CONGRESS SET OUT TO HELP DEVELOPMENTALLY DISABLED PEOPLE IT WAS PROVIDING FOR ONE OF THE MOST VULNERABLE GROUPS IN THE NATION. AN INDIVIDUAL IS CONSIDERED DEVELOPMENTALLY DISABLED WHEN SEVERE, CHRONIC DISABILITIES ATTRIBUTED TO MENTAL OR PHYSICAL IMPAIRMENTS ARE MANIFEST BEFORE AGE 22. SUCH DISABILITIES MUST CAUSE SUBSTANTIAL LIMITATIONS IN AT LEAST THREE AREAS OF MAJOR LIFE ACTIVITY AND RESULT IN THE NEED FOR SERVICES OVER AN EXTENDED PERIOD OF TIME. POSSIBLE LIMITATIONS MAY OCCUR IN THE AREAS OF SELF-CARE, RECEPTIVE AND EXPRESSIVE LANGUAGE, LEARNING, MOBILITY, SELF-DIRECTION, CAPACITY FOR INDEPENDENT LIVING, AND ECONOMIC INDEPENDENCE. WE ESTIMATE

THAT THERE ARE APPROXIMATELY 3.9 MILLION PERSONS WITH DEVELOPMENTAL DISABILITIES IN THE UNITED STATES, APPROXIMATELY TWO MILLION OF WHOM ARE OVER THE AGE OF 18. PERSONS SERVED IN RESIDENTIAL FACILITIES REPRESENT ONLY A SMALL PERCENTAGE OF THIS POPULATION; FOR EXAMPLE, ABOUT 146,000 PERSONS RESIDE IN MEDICAID FUNDED INTERMEDIATE CARE FACILITIES FOR THE MENTALLY RETARDED.

OVERALL PURPOSE OF THE DEVELOPMENTAL DISABILITIES PROGRAM

THE DEVELOPMENTAL DISABILITIES ACT OF 1984 ESTABLISHED THE FOLLOWING PRINCIPLES FOR THE DEVELOPMENTAL DISABILITIES PROGRAM:

PERSONS WHO ARE DEVELOPMENTALLY DISABLED SHOULD BE ABLE TO:

- EXERT CONTROL OVER THEIR OWN LIVES;
- ENGAGE IN INCOME PRODUCING WORK (INCLUDING COMPETITIVE EMPLOYMENT) OR PERFORM WORK WHICH WILL CONTRIBUTE TO A HOUSEHOLD OR COMMUNITY; AND
- USE COMMUNITY RESOURCES AND LIVE WITHIN THAT COMMUNITY.

THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES IS CHARGED TO ASSIST STATES TO:

- ASSURE THAT PERSONS WITH DEVELOPMENTAL DISABILITIES RECEIVE THE SERVICES NECESSARY TO ENABLE THEM TO ACHIEVE THEIR MAXIMUM POTENTIAL THROUGH INCREASED INDEPENDENCE, PRODUCTIVITY, AND INTEGRATION INTO THE COMMUNITY; AND,

- ESTABLISH AND OPERATE A SYSTEM WHICH PROTECTS THE LEGAL AND HUMAN RIGHTS OF PERSONS WITH DEVELOPMENTAL DISABILITIES.

THE LEGISLATION WHICH WE ADMINISTER CONTAINS FOUR MAJOR PROGRAM COMPONENTS. IT AUTHORIZES FUNDS FOR:

1) BASIC STATE GRANTS;

2) PROTECTION AND ADVOCACY GRANTS;

3) UNIVERSITY AFFILIATED FACILITY GRANTS; AND

4) SPECIAL PROJECT GRANTS.

BASIC STATE GRANTS:

BASIC STATE GRANTS HELP STATES TO PLAN, COORDINATE, AND ADMINISTER SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES. FORMULA GRANTS FUNDS ARE AWARDED TO EACH STATE TO SUPPORT THE STATE DEVELOPMENTAL DISABILITIES PLANNING COUNCIL. THE STATE COUNCIL, COMPRISED OF REPRESENTATIVES OF MAJOR STATE AND FEDERAL PROGRAMS, SERVICE PROVIDERS, AND DEVELOPMENTALLY DISABLED PERSONS AND THEIR FAMILIES, MONITORS THE SERVICE DELIVERY NETWORK AND PREPARES A THREE YEAR STATE PLAN. AS PART OF THAT PLAN, EACH STATE MUST PROVIDE SERVICES IN THE AREA OF EMPLOYMENT RELATED ACTIVITIES. IN ADDITION, THEY MAY SELECT UP TO TWO MORE OF THE FOLLOWING PRIORITY SERVICE AREAS:

o CASE MANAGEMENT;

o CHILD DEVELOPMENT SERVICES;

o ALTERNATIVE COMMUNITY LIVING ARRANGEMENTS.

IN FISCAL YEAR 1985 THE BASIC STATE GRANT PROGRAM SERVED 55,675 PERSONS. FUNDS FROM BASIC STATE GRANT HAVE PROVIDED "SEED MONEY" TO INITIATE NEW AND INNOVATIVE SERVICES. FOR EXAMPLE:

- CONNECTICUT

  A GRANT WAS AWARDED TO THE CORPORATION FOR INDEPENDENT LIVING WHICH EXPANDED OPPORTUNITIES FOR THE DEVELOPMENTALLY DISABLED TO LEAVE INSTITUTIONS AND RESIDE IN THE COMMUNITY. IN FISCAL YEARS 1984-1986, 144 INDIVIDUALS WERE MOVED FROM STATE INSTITUTIONS TO COMMUNITY SETTINGS.

- UTAH

  A GRANT WAS AWARDED WHICH PROVIDED 500 DAYS OF 24-HOUR CARE AND 600 HOURS OF TRAINED SITTER SERVICES FOR FAMILIES WITH A DEVELOPMENTALLY DISABLED MEMBER. THIS PROJECT PROVIDED RESPITE CARE WHICH WAS IMPORTANT TO THE WELL-BEING OF THE FAMILIES AND SUPPORTED COMMUNITY INTEGRATION.

- WASHINGTON

  A GRANT WAS AWARDED WHICH PROVIDED 17 SPECIAL EDUCATION PARENT ADVISORY COUNCIL TRAINING SESSIONS IN 26 SCHOOL DISTRICTS THROUGHOUT THE STATE. THE TRAINING INCREASED THE INVOLVEMENT OF PARENTS IN SECURING IMPROVEMENTS IN THE QUALITY OF SERVICES FOR YOUNG DEVELOPMENTALLY DISABLED CHILDREN.

PROTECTION AND ADVOCACY GRANTS:

PROTECTION AND ADVOCACY GRANTS ARE AWARDED BY FORMULA TO STATE PROTECTION AND ADVOCACY AGENCIES. THESE AGENCIES MUST BE INDEPENDENT FROM ANY ENTITY WHICH PROVIDES SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES AND MUST HAVE THE AUTHORITY TO PURSUE LEGAL, ADMINISTRATIVE, AND OTHER APPROPRIATE REMEDIES TO INSURE THE PROTECTION OF THE RIGHTS OF DEVELOPMENTALLY DISABLED INDIVIDUALS. THE PROTECTION AND ADVOCACY SYSTEM SERVED 52,000 PERSONS IN FY 1985, PROVIDING ASSISTANCE WITH PROBLEMS RELATED TO EDUCATION, EMPLOYMENT, TRANSPORTATION, VOCATIONAL REHABILITATION, MEDICAL SERVICES, ABUSE AND NEGLECT, HOUSING, ARCHITECTURAL BARRIERS, AND GUARDIANSHIP. IN ADDITION, THOUSANDS OF DISABLED PERSONS HAVE RECEIVED INFORMATION AND REFERRAL SERVICES FROM THE PROTECTION AND ADVOCACY SYSTEM.

UNIVERSITY AFFILIATED FACILITIES:

UNDER THE UNIVERSITY AFFILIATED FACILITIES PROGRAM, GRANTS ARE AWARDED TO SUPPORT A NATIONAL NETWORK OF 36 UNIVERSITY AFFILIATED FACILITIES AND 7 SATELLITE CENTERS. THESE FACILITIES PROVIDE ACADEMIC AND PROFESSIONAL TRAINING AND ENSURE THAT THERE IS A PROFESSIONAL AND PARAPROFESSIONAL

WORKFORCE PREPARED TO MEET THE SERVICE NEEDS OF THE DEVELOPMENTALLY DISABLED. APPROXIMATELY 57,000 INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES RECEIVE DIRECT SERVICES EACH YEAR FROM THE UNIVERSITY AFFILIATED FACILITIES AND SATELLITE CENTERS.

SPECIAL PROJECT GRANTS:

SPECIAL PROJECT GRANTS ARE AWARDED THROUGH THE HDS COORDINATED DISCRETIONARY FUNDS PROGRAM TO STATES, UNIVERSITIES, AND NON-PROFIT ORGANIZATIONS TO PROVIDE FINANCIAL ASSISTANCE FOR DEVELOPING NEW TECHNOLOGY AND APPLYING INNOVATIVE METHODS TO SUPPORT THE INDEPENDENCE, PRODUCTIVITY, AND INTEGRATION INTO THE COMMUNITY OF PERSONS WITH DEVELOPMENTAL DISABILITIES. IN FISCAL YEAR 1986, THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES' SPECIAL PROJECT GRANTS EMPHASIZED INCREASING OPPORTUNITIES FOR EMPLOYMENT OF PERSONS WITH DEVELOPMENTAL DISABILITIES. SPECIAL PROJECT GRANTS TOTALLED $1,483,593 AND ADDRESSED AREAS SUCH AS EMPLOYEE ASSISTANCE PROGRAMS, TRANSITION FROM SCHOOL TO WORK, EMPLOYMENT MODELS, AND MATCHING JOB VACANCIES AND INDIVIDUAL ABILITIES.

FEDERAL COORDINATION EFFORTS

AT THE FEDERAL LEVEL, THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES COORDINATES WITH VARIOUS DEPARTMENTAL AND OTHER AGENCIES THAT PROVIDE FUNDING FOR SERVICES NEEDED BY THE DEVELOPMENTALLY DISABLED, INCLUDING THE HEALTH CARE FINANCING ADMINISTRATION, THE SOCIAL SECURITY ADMINISTRATION, THE DEPARTMENT OF EDUCATION, AND THE DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT.

ONE SUCH COORDINATION EFFORT IS THE INTRADEPARTMENTAL WORK GROUP ON POLICIES AFFECTING MENTALLY RETARDED AND OTHER DEVELOPMENTALLY DISABLED PEOPLE. THE WORK GROUP WAS ESTABLISHED AS A FOLLOW-UP TO THE REPORT TO CONGRESS ON POLICIES FOR IMPROVING SERVICES TO MENTALLY RETARDED AND OTHER DEVELOPMENTALLY DISABLED PERSONS UNDER TITLE XIX OF THE SOCIAL SECURITY ACT CALLED FOR IN THE 1984 DEVELOPMENTAL DISABILITIES ACT. RECOGNIZING THE GOALS OF INDEPENDENCE, INTEGRATION AND PRODUCTIVITY, AND THE OBSTACLES THAT MAY PREVENT THESE GOALS FROM BEING REALIZED, SECRETARY BOWEN CHARGED THE WORK GROUP TO EXAMINE FEDERAL POLICIES AND PROGRAMS, INCLUDING MEDICAID-FUNDED INTERMEDIATE CARE FACILITIES, AND TO RECOMMEND

CHANGES THAT WILL INCREASE ACCESS TO COMMUNITY LIVING ARRANGEMENTS AND ENCOURAGE SELF-SUFFICIENCY. THE WORK GROUP, CHAIRED BY THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION, WILL FORWARD ITS RECOMMENDATIONS TO THE SECRETARY THIS YEAR.

ANOTHER COORDINATION EFFORT INVOLVES PARTICIPATION IN THE INTERAGENCY COMMITTEE ON DEVELOPMENTAL DISABILITES. THIS INTERAGENCY GROUP COORDINATES AND PLANS ACTIVITIES CONDUCTED BY FEDERAL DEPARTMENTS AND AGENCIES AS MANDATED BY THE DEVELOPMENTAL DISABILITIES ACT OF 1984. THE COMMITTEE, CO-CHAIRED BY THE COMMISSIONER OF THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES AND THE ASSISTANT SECRETARY FOR SPECIAL EDUCATION AND REHABILITATIVE SERVICES OF THE DEPARTMENT OF EDUCATION, HAS IDENTIFIED TWO PRIMARY AREAS OF EMPHASIS: COMMUNITY LIVING AND SUPPORTED EMPLOYMENT.

PRIVATE SECTOR EFFORT: EMPLOYMENT INITIATIVE CAMPAIGN:

THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES HAS ENGAGED THE PRIVATE SECTOR IN PROMOTING SELF-SUFFICIENCY FOR PERSONS WITH DEVELOPMENTAL DISABILITIES THROUGH THE EMPLOYMENT INITIATIVE CAMPAIGN. PRESIDENT REAGAN ANNOUNCED THE EMPLOYMENT INITIATIVE CAMPAIGN IN NOVEMBER OF 1983 AS PART OF THE NATIONAL

Decade of Disabled Persons. The campaign demonstrates that Americans with developmental disabilities can be a viable segment of the work force. The results to date have been most rewarding.

In the first two years of the campaign, approximately 87,000 workers with developmental disabilities have been employed in private sector jobs. They will earn about $400 million in gross annual taxable wages, while the combined savings in public support costs and services will total nearly another $400 million. This extraordinary accomplishment is due to the active support of corporations such as Radisson Hotels, Denny's Restaurants, the McDonalds Corporation, and trade associations, including the American Hospital Association, and the National Restaurant Association, among others.

The Employment Initiative Campaign has shown that, given proper support services, persons with developmental disabilities can be employed at worksites where persons without disabilities are employed.

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REAUTHORIZATION

IN ORDER TO CONTINUE OUR WORK TO PROVIDE CARE, TREATMENT AND OTHER SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES, WE SUPPORT REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT. A LEGISLATIVE PROPOSAL ENTITLED "DEVELOPMENTAL DISABILITIES ASSISTANCE AMENDMENTS OF 1987" WAS TRANSMITTED BY THE SECRETARY TO CONGRESS ON MARCH 9, 1987, AND WAS INTRODUCED AS H.R. 1871 BY REPRESENTATIVE MADIGAN ON MARCH 31, 1987. THIS PROPOSAL WOULD:

o EXTEND AUTHORIZATION OF APPROPRIATIONS FOR PROGRAMS UNDER THE ACT FOR THREE YEARS. APPROPRIATIONS WOULD BE AUTHORIZED FOR SUCH SUMS AS NECESSARY FOR EACH OF THE FISCAL YEARS, 1988, 1989, AND 1990.

o ADD FAMILY SUPPORT SERVICES AS A PRIORITY SERVICE AREA IN THE BASIC STATE GRANT PROGRAM. THIS PROPOSAL WOULD EXPAND AND PROVIDE CRUCIAL SUPPORTIVE SERVICES TO FAMILIES WHO CARE FOR THEIR DEVELOPMENTALLY DISABLED FAMILY MEMBER WITHIN THE HOME. FAMILY SUPPORT SERVICES ARE DEFINED AS SERVICES WHICH:

  - STRENGTHEN THE FAMILY'S ROLE AS PRIMARY CARE GIVERS;

- PREVENT OUT-OF-HOME PLACEMENT;

- REUNITE FAMILIES WITH MEMBERS WHO HAVE BEEN PLACED OUT OF THE HOME; AND

- MAINTAIN FAMILY UNITY.

FAMILY SUPPORT SERVICES MAY INCLUDE RESPITE CARE, PERSONAL CARE, PARENT TRAINING AND COUNSELING, AND OTHER SERVICES WHICH WILL SUPPORT THE WELL-BEING OF FAMILIES OF PERSONS WITH DEVELOPMENTAL DISABILITIES.

O CLARIFY THE DEFINITION OF SUPPORTED EMPLOYMENT TO STRESS COMPETITIVE EMPLOYMENT OF DEVELOPMENTALLY DISABLED INDIVIDUALS AT WORKSITES WHERE INDIVIDUAL WITHOUT DISABILITIES ARE EMPLOYED. THIS PROPOSAL REAFFIRMS OUR POSITION THAT DEVELOPMENTALLY DISABLED INDIVIDUALS SHOULD PARTICIPATE FULLY IN COMPETITIVE EMPLOYMENT AND NOT BE LIMITED TO SHELTERED WORKSHOPS OR OTHER PROTECTED POSITIONS DESIGNED EXCLUSIVELY FOR THE DEVELOPMENTALLY DISABLED.

O BROADEN THE CATEGORY OF FAMILY REPRESENTATIVES ON STATE PLANNING COUNCILS TO INCLUDE RELATIVES OR GUARDIANS OF FORMERLY INSTITUTIONALIZED PERSONS WITH DEVELOPMENTAL

DISABILITIES. STATES HAVE EXPERIENCED INCREASING DIFFICULTY IN IDENTIFYING INDIVIDUALS WILLING TO SERVE ON THE STATE PLANNING COUNCILS DUE TO THE SUCCESS OF DEINSTITUTIONALIZATION AND THE CONCOMITANT DECREASE IN THE AVAILABLE PARENT POOL. THIS PROVISION WOULD ASSIST STATES IN COMPLYING WITH THE PLANNING COUNCILS' COMPOSITION REQUIREMENTS BY EXPANDING THE AVAILABLE POOL OF PARENTS OR GUARDIANS ELIGIBLE TO SERVE ON THE COUNCIL.

CONCLUSION

IN CLOSING, I WANT TO ASSURE YOU THAT OUR POLICIES HAVE AND WILL CONTINUE TO FOCUS ON ATTAINING THE COMPLEMENTARY GOALS OF PROVIDING GREATER PROGRAM AUTHORITY AT THE STATE AND LOCAL LEVEL AND SUPPORTING IMPROVED PROGRAM EFFECTIVENESS, IN RECOGNIZING THE NEEDS, POTENTIAL, AND ACCOMPLISHMENTS OF PERSONS WITH DEVELOPMENTAL DISABILITIES.

THANK YOU, MR. CHAIRMAN, I WOULD BE HAPPY TO ANSWER ANY QUESTIONS.

Senator Harkin. Dr. Elder, thank you for your testimony.

Dr. Elder. You are welcome.

Senator Harkin. I just have a couple of questions. The first one focuses on the generic request for the money. Notwithstanding your own obvious personal and longstanding support for the Developmental Disabilities Act, is it possible that under the Administration's proposed generic appropriation of $2.2 billion for the 26 programs, which includes the Developmental Disabilities Act, that OMB could—and I emphasize the word "could"—direct you to zero-fund, for example, the Protection and Advocacy programs? Could that be possible?

Dr. Elder. Could they direct me?

Senator Harkin. Yes.

Dr. Elder. I am assuming I would have a rebuttal.

Senator Harkin. Well, you could have a rebuttal, but who would win the tussle? Who would win? I mean, let us not even take the extreme case of zeroing out. Let us just say they wanted to reduce the funding for the Protection and Advocacy program.

Dr. Elder. In our budget document that was sent to the Hill, there was a statement dealing with which programs had the highest priorities. In that narrative, the Developmental Disabilities Act was listed as one of the highest priorities in HDS.

Senator Harkin. I do not doubt that it is one of the highest priorities there. I am talking about OMB and the directives that they send out. And again, it is a concern of mine, especially on this Committee and on our Appropriations Committee, as we have had for some time, that I think we were elected to make some decisions like that——

Senator Stafford. Mr. Chairman, if you would yield, I would only suggest that Dr. Elder can win when she has differences with OMB provided this Subcommittee and the Full Committee and the House and Senate stand with her and not with OMB.

Senator Harkin. That is right, that is right—and if we specifically say these things, rather than the generic money that goes down; that is very true.

Well, my point is, I would hope that there would be support here on the Subcommittee and the Committee to make sure that we do make those authorization-appropriations priorities. I am sure we will.

Dr. Elder, have you read the recommendations made by the Consortium for Citizens with Developmental Disabilities regarding modification of the Act?

Dr. Elder. Have I read their entire document? Yes, sir, I have read it.

Senator Harkin. So you are aware of it. Do you have any comments on what they have said? They will be testifying later on as the last witness today. I was just wondering do you have any comments at all, general observations on their report and their recommendations?

Dr. Elder. I really did not study it, Senator, in terms of making definitive comments about their recommendations. If you would like me to submit some comments for the record, I would be glad to. I made some notes when I read it, but I do not have them with me.

Senator HARKIN. Okay. I just wondered if anything sprung to your mind right away, and if not, if you would look at it, and——

Dr. ELDER. Yes, I have read it, and I made lots of notes in the margin.

Senator HARKIN. OK, but nothing right now springs to mind. But if you would send up some of your thoughts on it——

Dr. ELDER. I would be glad to.

Senator HARKIN. Lastly, you have stated in your testimony at about the last page of it, that, "As a result of the employment initiative, over 87,000 people with developmental disabilities were placed in jobs in two years."

Dr. ELDER. Yes, sir.

Senator HARKIN. Could you please submit for the record documentation for this figure? It is pretty impressive.

Dr. ELDER. I would be glad to.

[The material referred to follows:]

ADMINISTRATION ON DEVELOPMENTAL DISABILITIES
EMPLOYMENT INITIATIVE
STATISTICAL SUMMARY

January 31, 1987
Page 1 of 2

ORGANIZATION	CY 1984 (GOAL 25,000)		CY 1985 (GOAL 50,000)		CY 1986 (GOAL 75,000)		CY 1987 (GOAL 75,000)		TOTAL (GOAL 225,000)	
	PLEDGES	PLACE-MENTS	PLEDGES	PLACE-MENTS	PLEDGES	PLACE-MENTS	PLEDGES	PLACE-MENTS	PLEDGES	PLACE-MENTS
A. FOOD SERVICE										
Canteen Corporation..			1,000						1,000	
Denny's.............			2,500						2,500	
Marriott............			2,000						2,000	
McDonalds...........			3,000		10,020				13,020	
National Restaurant Association........	20,000		20,000	14,000	16,000				56,000	14,000
Naugles.............	500		500						1,000	
Saga Corporation.....			500		100				600	
Safeway.............					25				25	
Pizza Hut					60				60	
B. HEALTH CARE										
American Hospital Association........	16,000				16,000				32,000	
Natl. Rehab. Hosp....					20				20	
C. AMER. HARDWARE							1,000		1,000	
D. INTER. FABRICARE							11,000		11,000	
E. EQUIP. SERVICING							4,000		4,000	
F. HORTICULTURE										
National Council for Therapy and Rehabilitation Through Horticulture.	2,500		2,500	1,367	3,015				8,015	1,367
Natl. Aborist Assoc.							5,000		5,000	
G. HOTELS/MOTELS										
Radisson............			100						100	
Marriott............					35				35	
Holiday Inn					200				200	
H. UTILITIES										
Puerto Rico Tele.....					2,000				2,000	

Continued - See Page 2 for Sum of Columns

ADMINISTRATION ON DEVELOPMENTAL DISABILITIES
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January 31, 1986
Page 2 of 2

ORGANIZATION	CY 1984 (GOAL 25,000)		CY 1985 (GOAL 50,000)		CY 1986 (GOAL 75,000)		CY 1987 (GOAL 75,000)		TOTAL (GOAL 225,000)	
	PLEDGES	PLACE-MENTS	PLEDGES	PLACE-MENTS	PLEDGES	PLACE-MENTS	PLEDGES	PLACE-MENTS	PLEDGES	PLACE-MENTS
I. MULTI-NATL. CORP.										
Rohm and Haas Co.....					160				160	
Southland Corp.......					2,400				2,400	
J. EDUCATIONAL INST.										
Univ. Affiliated Fac.			63		8				71	
Natl. Catholic Assoc.					15,000				15,000	
Greater Lawrence Educ. Collaborative					50				50	
K. AMER. RETAIL FED.					20,000		20,000		40,000	
L. FINANCIAL INST.										
Fleet Natl. Bank					30				30	
Caguas Federal Bank					10				10	
M. TRANSPORTATION										
Amer. Bus Association					3,000				3,000	
Amer. Port Authority					277				277	
N. CONSTRUCTION										
Plumbing & Heating					6,000				6,000	
O. PERFORMING ARTS										
Perform. Arts Theatre					500				500	
P. CIVILIAN/CONTRACTS					6,618				6,618	
Q. FULL EMPLOY. COUN.					250				250	
R. GOODWILL INDUST.			27,000						27,000	
S. COMM. AWARDS						28				
T. STATE PROFILES			219		92	53,244			311	
U. *OTHER	4,000				3,285				7,285	
TOTAL	43,000	/////// ///////	59,382	/////// ///////	105,155	53,272 //////	41,000		248,537	/////////
KIERNAN SURVEY	///////	25,000	////////	62,409	///////	//////			/////////	87,409

*Response Cards, R&D Grants & Regional Offices

Dr. **Elder**. Senator, I would like to add that during the first two years we were only counting people who had been in sheltered employment programs for adults a developmental disability and who moved from sheltered employment to competitive employment.

There are other aspects of the service delivery system that we should be looking at. My feeling is that there are many more people who, with the right kinds of supports, can move into competitive employment. We do have data on those 87,000 persons. Specifically, our data includes from what sheltered workshop or what day activity program they were in, and then where they were placed in a competitive job, how long they were retained in that position, and how much their earnings were.

I would also say that our retention data are better than some vocational rehabilitation programs.

Senator **Harkin**. I was just figuring here—you said there were 87,000 people, and they are going to earn about $400 million in gross annual taxable wages.

Dr. **Elder**. Right.

Senator **Harkin**. Just my preliminary division—and I am not saying it is accurate, but I think my math is fairly decent—that comes to about $4,500 per year per person.

Dr. **Elder**. That is not a very good wage, is it?

Senator **Harkin**. Well, I am just saying, $4,500 a year is not very good. I mean, that is the average—I am sure some make more and some make less—but as an average, that is not so good.

Dr. **Elder**. I agree with you. Basically what we are talking about is letting this Nation know that people who in many folks' minds have been looked upon as a throwaway population can in fact be gainfully employed. Many of us started work at minimum wages; that is not where all of us have stayed, but it is an opportunity for people to become part of the labor force, have some type of a work record, and then move from that to the next step if they have the competency to do it. It also should be noted that many of these people are not full-time employees. Some of them are 20-hour-a-week employees and have other types of support so that they can live. But yes, this is not a wage that you or I would be very pleased with.

Senator **Harkin**. Please forgive me. I am rather new to this. Maybe that is good: I do not know.

Dr. **Elder**. The good news is that people who previously were not gainfully employed in an integrated work setting, in a competitive job, are now doing that. This is quite an accomplishment for us in this field, because 25 years ago we would not have been talking about work at all. We would hardly have been talking about adult services.

Senator **Harkin**. Thank you very much, Dr. Elder.

Senator Weicker?

Senator **Weicker**. Thank you very much, Mr. Chairman. I look forward to serving with you on this Subcommittee. Let me say that there have been no two greater friends than Senator Harkin and Senator Stafford insofar as the disabled of this Nation are concerned. And I do not like to give up a chairmanship, but if I had to give it up, I could not think of anybody better than Senator Harkin. And indeed, as far as style is concerned, he is probably a lot smoother and nicer than I am, so I think that things will progress very well under his leadership.

I only have one quick question, which is really an add-on to Senator Harkin's. I have to say to you, Jean, that I really dislike it when the Administration sends people like you up here to testify, because I have clear mixed emotions. I think you are a very wonderful person. By the same token, I have to deal with the budget that the Administration sends up, and the budget is very contradictory to Jean Elder; I think that was sort of implied in the Chairman's question.

Let us face it—the generic appropriation that the Administration is recommending is $67 million less than that of a year ago.

Dr. **Elder**. That is about right.

Senator **Weicker**. So already you have a reduction. And who that reduction is going to fall on, I do not know, but none of the programs in the generic appropriation can afford any reduction. And that is what bothers me, I suppose, as much as anything the Administration does; it sort of throws the scraps into the arena for the least fortunate to fight over. And that is just not my vision of America.

So I have to repeat, again as a follow-up to the Chairman's question, just how do you think this is going to affect the specific program that brings us here today since the overall pot is substantially less than it was a year ago—assuming that the administration's proposal is going to be adopted, which I think is probably highly unlikely. I think Congress will do what is necessary here to bring it back up. But how do you jive that?

Dr. **Elder**. It is very difficult, sir. We have a budget that combines multiple programs under a generic heading. All of us have studied the budget thoroughly and we do know that it was less than it was last year. All I can do at this time is assure you that this program would fare well.

Senator **Weicker**. I appreciate your sentiment, but then, let me give the rejoinder: I know this program is going to do well.

[Laughter.]

Dr. **Elder**. I have always enjoyed being your straight man.

Senator **Weicker**. I yield, Mr. Chairman.

Senator **Harkin**. Senator Stafford?

Senator **Stafford**. Thank you, Mr. Chairman.

When I said earlier that I had served under Jennings Randolph on this Committee, I should have noted that for six years, this Committee was very ably chaired by my friend Lowell Weicker, and I was glad to serve under him, as I am now with Senator Harkin.

It occurred to me as I listened to some of the questions that with 87,000 people working now and $400 million being earned in taxable income, working out to about $4,500 a person, that is a pretty low salary, but it means that 87,000 people have a much better quality of life, I would guess. Isn't that a fact?

Dr. **Elder**. I would agree with you, Senator, yes.

Senator **Stafford**. I have seen some of them, and I know they are much happier working than they would be left at home as they were 25 years ago.

Let me ask just one or two quick questions. Recommendations have been made to eliminate the requirement to select employment-related activities as a priority as it has "served its purpose". Do you feel that this requirement should be eliminated?

Dr. ELDER. No, sir, I do not.

Senator STAFFORD. The Administration's proposal contains a new priority for family support services. Do you feel that this should be a required priority for all States, or as an option?

Dr. ELDER. I would like to have it as an option for all States; 21 States already have family support legislation that they passed at the State level. Some of those programs have a cash subsidy that they provide to families. Some have in-kind support services. Some are a combination of the two. My former home State has both, and they also have a magnificent evaluation component, so that at the end of each year, they have some sense of what good that family support system has done.

I firmly believe that, historically, there has been a lack of services in this Nation for people who are developmentally disabled. Although we have given a lot of lip service to families as caregivers, we have not reflected that view in our public policy. And given that we have an opportunity to reauthorize the DD Act, and it has been a cutting edge piece of legislation, I was hopeful that Congress would look with favor upon this recommendation from the Administrative Branch. I feel very strongly that parents can and want to be the first primary caregivers to developmentally disabled persons who live with them. Often they just need a little bit of help.

Senator STAFFORD. Thank you very much. Do your records indicate, or could you tell us, the fate of people who have been employed under these programs? Are they able to retain their jobs on a continuing basis? In other words, are most of those who were employed a year ago still employed at the same job?

Dr. ELDER. Yes, sir, they are. And as the good Senator from Iowa asked me for the record, I will submit both the report for the first year and the report for the second year. And the retention figures look very good—about 77 percent. If you ask me are they in the same job, I cannot tell you that; but I know that they are gainfully employed. And as we look at our information-gathering for the third year, data on job shifts will be very interesting to me.

Our second year study asked people at the State level about their knowledge of 1619(a) and (b) of the Social Security Act: did they know about these provisions and were they using them? The information available indicates that not too many people know about 1619(a) and (b), do not know about this recent change in the law, and therefore do not take it upon themselves to access that information.

Human Development Services continues to work—we had a meeting this week—with the Social Security Administration on ways to get that information out to our regional offices and to our district offices, so that people will know what is available and what is in the pipeline.

[Information supplied for the record follows:]

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United States Senate

COMMITTEE ON LABOR AND
HUMAN RESOURCES
WASHINGTON, DC 20510-6300

April 10, 1987

Jean Elder, Ph.D
Acting Assistant Secretary for the
Office of Human Development Services
Humphrey Building, Room 315F
200 Independence Avenue S.W.
Washington, D.C. 20201

Dear Dr. Elder:

Thank you for testifying before the Subcommittee on the Handicapped regarding the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. It was a pleasure to have you as a witness. Your testimony was informative and helpful.

As you recall, when you testified, I asked that you provide us with some follow-up material for the record. I look forward to receiving:

1. Your comments on the recommendations made by the Consortium for Citizens with Developmental Disabilities regarding modification to the substantive provisions of the Developmental Disabilities Assistance and Bill of Rights Act. We already know your posision on the authorization levels and your "generic" appropriation proposals and thus, comments on these recommendations are not necessary.

2. Additional information on the 87,000 persons with developmental disabilities who have benefitted from the "Employment Initiative". Please include information regarding the nature and severity of the disabilities and any follow up data on these individuals. Also include the following information:

--What type of follow up has occured on the individuals who have become employed as a result of this initiative?

--What are the types of disabilities and the degrees of severity of these individuals who are now employed?

--Of those who were employed during the first year of the effort, how many are still employed at there initial job site?

Additionally, there are a number of questions to which my colleagues on the Subcommittee and I would appreciate your response. Please provide me with the following:

1. Section 108 of the Act directs the Secretary of Health and Human Services to establish an interagency committee to coordinate and plan activities conducted by the Federal departments and agencies for persons with developmental disabilities.

--How regularly does the committee meet?

--Which agencies have been represented at the meeting?

--What have been the efforts of the Committee in the areas of community living and supported employment?

--Have there been other efforts from the Administration on Developmental Disabilities designed to involve other agencies in initiatives to improve services to the developmentally disabled?

2. In 1984, Congress mandated a study on the Intermediate Care Facilities for the Mentally Retarded. Would you summarize the recommendations that were made with respect to Title XIX of the Social Security Act and the waiver program under Section 1915(c) of the Social Security Act? How have these recommendations been implemented?

3. How has the requirement for State Councils and Protection & Advocacy Systems to submit annual reports to the Secretary affected their service delivery to individuals with developmental disabilities? In what ways have these requirements increased the accountability of the program?

Jean Elder, Ph.D.
April 10, 1987
Page Three

4. Would you recommend that the definition of supported employment included in the Rehabilitation Act Amendments of 1986 replace the supported employment definition currently in the Developmental Disabilities Act?

I look forward to receiving your responses to these questions and thank you in advance for your continued assistance to us as we consider the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. Please provide me with your written comments by April 23, 1987 when the record of the hearing will be closed.

Sincerely,

Tom Harkin
Chairman, Subcommittee
on the Handicapped

TH/kb

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of
Human Development Services

Office of Assistant Secretary
Washington DC 20201

MAY 1 1987

The Honorable Tom Harkin
Chairman, Subcommittee on the Handicapped
Committee on Labor and Human Resources
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

Thank you for the opportunity to testify before the Subcommittee on the Handicapped regarding reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. I am pleased to provide the following information in response to your letter of April 10, 1987:

1. Regarding the recommendations made by the Consortium for Citizens with Developmental Disabilities, enclosed are comments in response to eight of the major recommendations made by the Consortium (Enclosure 1).

2. Two surveys documenting the number of persons with developmental disabilities entering competitive employment were conducted by the Development Evaluation Clinic, a University Affiliated Facility (copies of both surveys are enclosed, reference Enclosures 2 and 3). As the July 1986 survey indicates, the facilities did follow-up on persons employed after 60 days and after 22 weeks. They found the retention rate to be 77.4% after 60 days and 73% after 22 weeks (reference Table 15 of the survey). The survey also includes information about the nature and severity of the disabilities, specifically:

- Regarding type of disability, 35% were mentally retarded, 10% had serious emotional problems, 17% were sensory impaired and 38% were physically impaired.

- With respect to degree of severity, 33% were reported as being in the severe/profound category, 15.5% in the moderate category, 10.9% were in the mild retardation category, and 40.3% had IQ's of 70 and above (reference Table 6 of the survey for both type of disability and degree of severity).

- You asked how many of the individuals who were employed during the first year of the effort are still employed at their initial job site. We do not have that information. The suvery reports on follow-up after 60 days and 22 weeks on the job as required by the Department of Labor. Experience has been that the first 60 days are critical in job retention, and those individuals that make it past the first 60 days stay on the job for a year or longer.

3. The Interagency Committee on Developmental Disabilities meets on a regular basis. Recent meetings were held on March 27, 1986; May 21, 1986; July 23, 1986; and November 4, 1986. The next meeting is scheduled for May 5, 1987.

Agencies represented have included the Department of Health and Human Services, Department of Education, Department of Justice, Department of Labor, National Council on the Handicapped and the National Institute of Child Health and Human Development. (A complete listing of representatives is located at Enclosure 4.)

Regarding the efforts of the Committee in the areas of community living and supported employment, the focus has been on sharing information and discussing policies in these areas. I have enclosed an example of one product based on work done by the Committee, an Information Memorandum on activities which support employment of individuals who are developmentally disabled, which was disseminated to the Developmental Disabilities network (reference Enclosure 5).

The Administration on Developmental Disabilities (ADD) works actively with other agencies to improve services to the developmentally disabled. For example, ADD participates as a member of the Interagency Committee on Handicapped Research and the Intradepartmental Work Group on Policies Affecting Mentally Retarded and Other Developmentally Disabled People. ADD also works with the Alcohol, Drug Abuse and Mental Health Administration, National Institute for Mental Health, regarding P.L. 99-319, Protection and Advocacy for Mentally Ill Individuals Act of 1986.

4. I have enclosed a copy of the Department's Report to Congress on Policies for Improving Services for Mentally Retarded and other Developmentally Disabled Persons Served Under Title XIX of the Social Security Act, which includes a summary of the Department's recommendations (Enclsoure 6). Please note that as a follow-up to this report, the Secretary established an Intradepartmental Work Group on Policies Affecting Mentally Retarded and Other Developmentally Disabled People to further examine current policies and make recommendations as needed. The Work Group, chaired by the Assistant Secretary for Planning and Evaluation, will be forwarding its recommendations to the Secretary later this year.

5. As a result of requiring State Councils and Protection and Advocacy (P&A's) systems to sumbit annual reports, the Administration on Developmental Disabilities is now aware on an annual basis of the major accomplishments of each State program. We have comprehensive data on the number of persons receiving direct services through the Basic State Grant program as well as the major accomplishments relative to systems change and legislative impact at the State and local levels on behalf of persons with developmental disabilities. For the P&A program, we know how many cases were handled as well as the major care problem areas on a State-by-State and national basis. We now know more about program accomplishments, which provides increased accountability.

6. The Department has proposed that the definition of supported employment currently in the Developmental Disabilities Assistance and Bill of Rights Act, as amended, be modified in reauthorization legislation. The new definition we are proposing is designed to be as consistent with the Rehabilitation Act Amendments of 1986 as possible, given the difference in laws and populations served. For example, our proposed definition incorporates the description of persons for whom supported employment is appropriate from the definition found in the Rehabilitation Act Amendments, but emphasizes competitive employment and integrated work settings. We believe that these changes will improve implementation of our legislative mandate, and recommend that the definition in our proposed bill be adopted.

I appreciate your interest in and support of programs for persons with developmental disabilities, and look forward to working with you in the future.

Sincerely,

Jean K. Elder

Jean K. Elder, Ph.D.
Assistant Secretary for
Human Development Services-Designate

Enclosures (6)

ENCLOSURE ONE

The Consortium for Citizens with Developmental Disabilities Recommendation Part A, Issue #5. The state optional priority area should be fully reinstated and its selection should be at the discretion of the States.

OHDS Comment: States may feel that they have unique service needs that could be best addressed through the priority service area provision. However, the current legislated priority areas (alternative community living arrangement services, employment related activities, child development services, and case management services) already provide for developing a State plan which address individual State needs, therefore, a legislative change is not necessary.

The Consortium for Citizens with Developmental Disabilities Recommendation Part A, Issue #6. The language permitting the "provision of specialized services" in the priority areas should be deleted and the activity permitting "model service programs" should be modified to clarify that such programs are for demonstration purposes (e.g., model demonstration programs).

OHDS Comment: The current legislative language should be retained as States should have the flexibility to fund whatever type of services the State determines as needed. States should be able to continue to fund "model service programs" if they wish to do so. This proposal would force States to fund only model service programs as narrowly defined by the Consortium for Citizens with Developmental Disabilities.

The Consortium for Citizens with Developmental Disabilities Recommendation Part A, Issue #7. Language to include "policy analysis and educating policy makers" should be added to the definition of the term "service activities."

OHDS Comment: Developmental Disabilities Councils under the current statute have the authority to carry out the activities described by the Consortium. However, these activities must be supported out of the portion of funds allocated to the State for planning activities (35% provision). We see no problem with defining these types of activities as service activities as long as they are not considered service activities under the priority services. We would not concur with spending priority service funds on these types of activities (65% provision). The types of activities to be conducted under the priority services area should remain as currently written in the legislation.

The Consortium for Citizens with Developmental Disabilities Recommendation Part D, Issue #2. The UAF program should be expanded to include a UAF in every State.

OHDS Comment: There are merits to expanding the UAF network but such an expansion must be done in accord with a well reasoned process designed to elicit the highest quality programs, capable of fulfilling UAF goals and objectives.

The Consortium for Citizens with Developmental Disabilities Recommendation Part D Issues #3, #4, #5 and Part E Issues #2, #3, #4. Funds for specific areas of interest for both the UAF program and special projects should be established.

OHDS Comment: Earmarking money for special areas through legislation limits program flexibility to respond to both current and future issues in support of the developmentally disabled. We welcome and encourage suggestions from the field regarding topical areas to be funded as Special Projects.

ENCLOSURES 2, 3, 6 : SEE COMMITTEE FILES

The Consortium for Citizens with Developmental Disabilities Recommendation Part B, Issue #3. Eliminate the requirement to select employment related activities as a Federal priority area.

OHDS Comment: The "mandated" employment related activities priority service area started in FY 1987, therefore, activities in support of this imporatnt service area have only recently been initiated. Based on the interest we all have regarding the employment of developmentally disabled individuals and the initial successes being achieved, such as the ADD Employment Initiative, we recommend that the Developmental Diabilities Assistance and Bill of Rights Act, as amended, remain as currently written.

The Consortium for Citizens with Developmental Disabilities Recommendation Part B, Issue #9. The State Plan should indicate what resources are available in the State for people with developmental disabilities who do not have mental retardation.

OHDS Comment: The State Plans already address the service needs of all developmentally disabled individuals. To specifically identify the resources for developmentally disabled individuals who do not have mental retardation is a categorical approach which diminishes the intent of the functional definition. In addition, such a reporting requirement would be burdensome to the States.

The Consortium for Citizens with Developmental Disabilities Recommendation Part C, Issue #6. A carryover of 10 percent of the yearly allotment for the P&A's should be allowed.

OHDS Comment: The Protection and Advocacy agencies operate on 100 percent Federal funding and there are problems for these agencies if there is a significant delay in the annual appropriation at the beginning of the fiscal year. However, there is no issue when funds are appropriated and awarded on a timely basis; therefore, a change to the legislation is not necessary.

ENCLOSURE FOUR

INTERAGENCY COMMITTEE ON DEVELOPMENTAL DISABILITIES

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Page 2 - Interagency Committee on Developmental
Disabilities

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ENCLOSURE FIVE

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration on Developmental Disabilities

1. Log No. ADD-IM-86-3	2. Issuance Date: 6/12/86
3. Originating Office: Administration on Developmental Disabilities	
4. Key Word: DD Employment	5. Interagency Committee
6.	7.

INFORMATION MEMORANDUM

MEMORANDUM TO: Directors, State Administering Agencies, Chairpersons, State Planning Councils, Executive Directors, State Planning Councils Directors, University Affiliated Facilities and Satellite Centers

SUBJECT : Activities Which Support Employment of Individuals Who Are Developmentally Disabled

CONTENT : The Administration on Developmental Disabilities is forwarding the attached information papers to support your individual efforts to promote the employment of individuals who are developmentally disabled. These papers reflect a growing level of activity relating to the Employment Initiative and services to persons who are developmentally disabled.

This information was presented at the Interagency Committee on Developmental Disabilities on March 27, 1986. This information includes projects from the Social Security Administration/HHS; Employment and Training Administration/DOL; Office of Social Services Policy/Assistant Secretary for Planning and Evaluation/HHS; and Health Care Financing Administration.

ATTACHMENT : Informational Papers

Informational Papers on
Activities Which Support
Employment of Individuals
Who Are Developmentally Disabled

Presented:
Interagency Committee
on Developmental Disabilities
March 27, 1986

Social Security Administration

Office of Disability

FY 1986 Priorities for Services to Persons With Developmental Disabilities

1. Medical Benefit Protection Demonstration Project

   In FY 1986, the Social Security Administration and Health Care Financing Administration, in conjunction with the Office of the Assistant Secretary of Special Education and Rehabilitative Services in the Department of Education, will develop a Medical Benefit Protection Demonstration Project for Social Security disability insurance (SSDI) beneficiaries. This project will be designed and conducted with several major American corporations and will demonstrate the employment incentive effects of primary employer health benefit coverage and continuing secondary Medicare insurance coverage for groups of SSDI beneficiaries who now receive Medicare benefits. A special focus of the project is medical benefit protection and employment for the developmentally disabled to demonstrate the effectiveness of providing job opportunities and medical benefit protection in assisting this group to return to work and leave the SSDI rolls.

2. Employer Based Initiative (EBI) Grants

   In September 1985, SSA awarded 15 grants to public and private rehabilitation organizations throughout the country to demonstrate innovative approaches to encourage SSDI beneficiaries to return to employment. Most of these projects will provide services to SSDI beneficiaries having a variety of different impairments. However, several projects will focus on persons with developmental disabilities.

   o City of Lawrence, Massachusetts
     Department of Training and Manpower Development

     The City of Lawrence will use its Job Training Partnership Act program in conjunction with organizations serving the disabled, to demonstrate effective vocational rehabilitation and employment services for SSDI beneficiaries. Several of the major organizations providing SSDI beneficiaries for the project serve the mentally retarded and developmentally disabled: Greater Lawrence Educational Collaborative; Greater Lowell Educational Collaborative; and Citizens League for Adult Special Services.

4. Focus Group Interview Project

SSA is conducting focus group interviews with beneficiaries to examine their understanding and use of existing work incentives and make recommendations related to improved communication with beneficiaries. As a part of this project we will include a focus group of parents of developmentally disabled beneficiaries as recommended by the Office of Special Education and Rehabilitative Services, Department of Education.

SERVICE TO THE HANDICAPPED
EMPLOYMENT AND TRAINING ADMINISTATION
U.S. DEPARTMENT OF LABOR

JOB TRAINING PARTNERSHIP ACT (JTPA)

- Title II A authorizes local training and employment programs for economically disadvantaged youth and adults through block grants to States.

  - Various provisions and interpretations are designed to assist the handicapped:

  1. Law defines a handicapped individual as any individual who has a physical or mental disability which for such individual constitutes or results in a substantial handicap to employment.

  2. Law provides that up to 10 percent of the participants in a Service Delivery Area (SDA) may be individuals not economically disadvantaged if such individuals has "encountered barriers to employment". Such individuals include the handicapped.

  3. The Department of Labor informed the Governors (July 1983) that handicapped youths may be considered "a family of one" in terms of income-eligibility for JTPA Services. This means that handicapped youths may qualify for services limited to economically disadvantaged persons even though total family income is above the qualifying line.

- The Following table presents the latest available data on services to the handicapped under Title II-A of JTPA. (JTPA allocations and program data are based on Program (rather than fiscal) Years covering periods from July 1 through June 30).

HANDICAPPED, TITLE IIA
[Percent Distribution]

Selected Characteristics	Transition Year Oct. 1983-June 1984	Program Year 1984 July 1984-June 1985
Total Enrollees	44,900	65,300
Sex		
Male	61%	62%
Female	39	38
Minority Status		
White (excluding Hispanic)	71	77
Black (excluding Hispanic)	21	16
Hispanic	5	5
Other	3	2
Age at Enrollment		
Youth (under 22)	42	47
Adults (over 21)	58	54
Economically Disadvantaged	90	91
Receiving AFDC at Application	10	10
Receiving Public Assistance (Including AFDC) at Application	32	31
Unemployment Compensation Claimant	7	6
Education Status		
School dropout	19	18
Student (High school or less)	23	30
High school graduate (or more)	57	52
Barriers to Employment		
Limited English	2	3
Handicapped	100	100
Offender	10	10
Displaced Homemaker	3	3
Initial Program Assignment		
Classroom Training	36	35
On-the-Job Training	19	17
Job Search Assistance	21	20
Work Experience	12	13
Other Services	12	15
Total Terminees	25,800	50,000
Entered Employment Rate	64	57
Average Hourly Wage	$4.20	$4.43

SOURCE: Job Training Longitudinal Survey

JTPA TITLE III

JTPA Title III provides training and other services to workers who have been dislocated at the work place (plant closing or mass layoffs). Program Year (PY) 1984 data show the following concerning handicapped participants:

- 3,500 Enrollees
- 30 percent Minorities
- 2,900 Terminees
- 1,900 Entered employment (65.5 percent)
- $5.54 Average wage at termination
- 16.2 Weeks - Median length of stay in the program

There were 74,800 enrollees overall in Title III programs for PY 1984. Overall, 70% entered employment at an average wage of $6.15. Thus, the entered employment rate for handicapped participants compares quite favorably.

> Note: Caution is advised concerning the reliability of Title III data because of the limited sample size of a number of the variables.

SOURCE: Job Training Longitudinal Survey.

National Association of Rehabilitation Facilities (NARF) $300,000

The National Association of Rehabilitation Facilities has been funded nationally since 1967 to provide on-the-job training for handicapped persons in rehabilitation and other health facilities. NARF has provided training and job placement for over 4000 handicapped individuals.

National Federation of the Blind (NFB) $244,000

The National Federation of the Blind has been funded nationally since 1979 to provide placement of blind participants in competitive, unsubsidized employment, primarily by matching the qualifications of blind persons with the needs of employers through a volunteer network in 50 States. NFB has provided placement for over 600 blind individuals.

Goodwill Industries $512,000

Goodwill Industries has been funded nationally since 1977 to provide multi-occupational in-house training and job placement to physically and emotionally disabled, mentally retarded, deaf, blind and other handicapped persons. Goodwill has trained and placed in unsubsidized employment over 6000 handicapped persons.

Mainstream, Inc. $350,000

Mainstream, Inc., was funded as a national contract from 1975 through 1983 to provide employers with information concerning the special problems of the handicapped in employment. In 1983 Mainstream was funded to operate, on an experimental basis, a job bank for handicapped individuals in Dallas and Washington, DC. Since 1983 Mainstream has placed over 800 handicapped individuals in employment.

Chavez and Associates Institute $500,000

Chavez and Associates Institute has been funded nationally since 1984 to train handicapped persons in computer services, word processing, private investigation and business/financial occupations, and to provide job placement services. To date over 300 handicapped individuals have been trained and 220 have been placed in employment.

Office of Social Services Policy
Department of Health and Human Services

Cross-Cutting Aging and Disability Synthesis

FY 1986 $100 (Evaluation)

Each of the major operating divisions within the Department as well as Labor, HUD and Education engage in program development, research and evaluation intended to promote the economic and physical self-sufficiency of aged and disabled populations. This project provides the capacity, on a short term basis, to synthesize and assess what is know about cross-cutting aging and disability issues and how information can be applied to particular policy development activities.

Approaches to Coordinating Health, Habilitation, Vocational and Employment Services for the Mentally Retarded

FY 1986 $110 (Policy Research)

The purpose of this study is to examine Federal, State and local policies and practices which support or impede the coordination and delivery of a broad spectrum of adult services including vocational and pre-vocational assistance. This study will identify successful State practices which capitalize on the flexibility of the current reimbursement system and to share these practices with other States; and to identify the legislative, regulatory and administrative barriers at all levels of government which impede coordinated service delivery as well as the approaches employed in overcoming these barriers.

Recent HCFA Activities

- HCFA has drafted proposed new ICF/MR regulations to clarify and update the standards that ICFs/MR must meet in order to participate in the Medicaid program. These draft regulations are designed to focus on the provision of active treatment to clients, provide better methods for assessing quality of care and maintain essential client protections. The proposed regulations also take into account the decrease in the average size of institutions and the changes necessitated by litigation, legislation, research and technological advances that influence the way clients are identified, assesed and provided services.

- HCFA has issued "look behind" procedures and has required its Regional Offices to conduct "look behind" surveys of at least five percent of its certified Medicaid ICFs/MR. While it is the State's responsibility to survey facilities for compliance with certification requirements. the Secretary, DHHS has the authority to make independent determinations of compliance, called "look behind" surveys for ICFs/MR. Each Regional Office has at least one developmental disabilities specialist designated to participate in this effort. In FY 1985 HCFA performed 464 "look-behind" surveys. For FY 1986 725 total surveys are planned.

- HCFA has prepared an instruction on the educational services exclusion in ICFs/MR (42 CFD 441.13(b). This instruction explains the distinction between educational services and covered intermediate care facilities services for the mentally retarded and the manner in which the prohibition against Federal Medicare payment for educational services should be applied in the ICF/MR setting. HCFA has also met with the Technical Advisory Group (TAG) of State Medicaid Directors to discuss a similar draft of an instruction on vocational training.

- On September 30, 1983, HCFAs Office of Research and Demonstrations began a 3-year project to assess the changes made in the Medicaid program as a result of recent legislation. The Home and Community-Based Waiver program evaluation is a part of this effort. Preliminary findings (as of June 1, 1984) indicate:

  - Approximately 53,000 people had been provided services under a home and community-based waiver and approximately 17,000 of these were MR/DD.

  - There is a larger penetration rate into the ICF/MR population (about 11.3 percent) than into the Medicaid institutionalized long term care aged population (about 2.5 percent).

WORK INCENTIVES FOR THE DEVELOPMENTALLY DISABLED UNDER MEDICARE AND MEDICAID

The Medicare and Medicaid programs are designed to provide medical and remedial services to persons who qualify for benefits on the basis of age or disability and certain other criteria. Under both programs, the definition of "disability" is closely tied to the concept of a beneficiary's inability to work. However, both Medicare and Medicaid contain incentives for beneficiaries to earn their way to self-sufficiency with reduced fear of losing needed medical benefits.

The Medicare program offers:

- A 15-month extension of Medicare benefits (following a nine months period of trial work) to those who lose eligibility for Social Security benefits because they are employed.
- Elimination of a second Medicare waiting period when individuals become re-entitled to disability benefits. This allows those who become disabled a second time to resume Medicare benefits during the same month as they begin to receive Social Security benefits. If the individual had not previously completed a 24-month qualifying period, the earlier months of entitlement can be counted in determining when Medicare begins.
- Various demonstrations exist (within SSA) to test promising but as yet untried work incentives for the disabled.

The Medicaid program:

- Medicaid can be continued during a trial work period during which a disabled individual may test his ability to work. The period extends for up to nine months.
- In addition, under the demonstration authority of Section 1619(b) of the Social Security Act, individuals can continue to be eligible for Medicaid even if their earnings are too great to constitute "disability" under the normal program. This special eligibility for Medicaid benefits continues so long as the individual: (1) continues to have a disabling impairment; (2) except for earnings, continues to meet all other requirements for SSI eligibility; (3) would be seriously inhibited from continuing to work by the termination of Medicaid eligibility; and (4) has earnings that are not sufficient to provide a reasonable equivalent of the benefits.
- States have the option to offer AFDC recipients the opportunity to participate in a work program where the State supplements participants' wages. Participants who would be eligible for AFDC if their wages were not supplemented may continue to receive Medicaid benefits.
- As a work incentive, Medicaid recipients who return to work are entitled to disregard income spent on work expenses (up to $75 per month) and child care expenses (up to $160 per child per month) for purposes of determining eligibility. After disregarding work expenses, $30 plus 1/3 of the remaining income may be disregarded from income to extend Medicaid eligibility for up to 4 months.

MEDICAID SERVICES STATE BY STATE

Basic Required Medicaid Services

October 1, 1984

[illegible]

Optional Services in State Medicaid Programs

[illegible]	[illegible]
[illegible]	[illegible]

Services for Age 65 or Older in TB Institutions

Services for Age 65 or Older in Mental Inst.

[illegible] Percentages are rounded and effective as of October 1, 1984.

[illegible]

*Report of services not received from these states.

Department of Health & Human Services
Health Care Financing Administration
Office of Intergovernmental Affairs

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EMPLOYMENT SURVEY FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

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Foreword

This study was an outgrowth of the increased efforts of the Federal Administration on Developmental Disabilities through the Employment Initiative to increase employment opportunities for individuals who are developmentally disabled. Community based rehabilitation facilities have played an important role in that initiative. As programs catch up with technology, rehabilitation facilities are in the forefront of implementation. Rehabilitation facilities are the first, outside of the University, to implement improved procedures. This striving for better services for persons who are disabled is illustrated in the rehabilitation outcomes as graphically displayed in this document. A 40 percent increase in competitive placements is a statistic of which facilities can be proud. The information depicted in this document is more, however, than mere statistics. It reflects the dedication of an industry to those whom it serves.

James A. Cox, Jr.
Executive Director

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Executive Summary

The role of employment in the lives of adults with developmental disabilities has received a considerable amount of attention during the past few years. Several initiatives have been undertaken by the federal government to stimulate activity designed to assist developmentally disabled adults to more effectively enter the world of work. Through grants from the Administration on Developmental Disabilities, Dr. Jean K. Elder, Commissioner, efforts such as the Employment Initiative of the Department of Health and Human Services have begun to document the movement of adults with developmental disabilities into competitive employment.

As part of this initiative, the Developmental Evaluation Clinic (DEC) of Boston Children's Hospital received a grant from the Administration on Developmental Disabilities to examine current employment activities among organizations providing vocational services. The DEC is a University Affiliated Facility having extensive experience placing developmentally disabled persons into employment.

As a means of documenting the numbers of employed adults with developmental disabilities, the DEC conducted a survey of 1,629 agencies, facilities and organizations throughout the United States. A total of 512 responses was received, a 31.4 percent rate of return. The response rate was generally distributed throughout the fifty states and is felt to reflect the activities occurring throughout the country.

The data received documented vocational service activities during the twelve month period from October 1, 1983 to September 30, 1984. From the 512 facilities responding, the total number of disabled persons receiving services was 96,823. Three quarters of the facilities served 200 or fewer persons while 13 percent served 300 or more persons. The largest number of facilities responding, a total of 90 facilities, served from 26 to 50 disabled persons.

Of these disabled persons receiving vocational services, 58.2 percent or 56,334 were reported to "fit" the functional definition of "developmental disabilities." Of this group, 12.6 percent or 7,075 were placed in either part or full-time competitive employment. More than twice that number, or 26 percent entered part or full-time sheltered employment.

As a means of examining job retention, each facility was asked to report the number of those entering competitive employment who remained on the job for more than sixty days. The retention rate for full-time competitive employment was greater than that for part-time employment (76.5 percent and 74.2 percent respectively). The overall retention rate was reported to be 75.9 percent.

Facilities also reported that 5,028 adults had been placed in competitive employment during the previous twelve month period (October, 1982 to September, 1983). Given the total number placed during the current survey period (7,075), this data shows a 40.7 percent increase in the number of adults with developmental disabilities placed in either part or full-time competitive employment.

A wide range of competitive job titles were reported. Most persons (72.3 percent) went into more typical entry level positions (i.e., janitorial, assembly, food preparation, etc). One out of every nine however, entered less traditional jobs such as computer programmers, printers, tax examiners, test technicians and taxi cab drivers.

Although the difference is not significant, the data did show that the mean age for those entering sheltered employment was four years older than for those entering competitive employment. There was no significant difference in age range between those entering competitive employment as compared to those entering sheltered employment.

Data reporting hours worked and average earnings for those engaged in competitive employment showed that the hourly wage for full-time competitive work was $3.74 per hour and $3.46 per hour for part-time employment. Average hours worked for those in full-time employment were 38 hours per week and 19 hours per week in part-time employment. Estimated annual earnings for full-time employment were $7,333 and $3,392 for part-time employment.

Estimates of the benefits and costs were developed utilizing a projected national total of 22,510 persons placed in either full or part-time competitive employment. Gross annual earnings adjusted to reflect an employment retention rate of 75.9 percent were estimated to be in excess of $107 million. Tax contributions by these developmentally disabled employees, estimated reductions in transfer payments, and estimated savings in costs for alternative programs were projected to be approximately $135 million annually.

The above estimates are based upon projections from the actual data of 7,075 adults with developmental disabilities from the 512 surveys received. Had 1,629 adults with developmental disabilities we placed in full or part-time competitive employme throughout the United States during the period fro October 1, 1983 to September 30, 1984.

I. INTRODUCTION

Employment has long been viewed as both a means of economic self sufficiency and personal/professional identity (Will, 1984). The concept of work and the place that work occupies in the social structure of the United States has been central to the establishment of a sense of belonging for most adults (Kiernan & Start, in press). Indeed, the identity of many individuals is intrinsically tied to the engaged occupations (Wright, 1980). From a macroeconomic perspective, indicators such as unemployment rates as well as labor force participation ratios are frequently viewed as indicators of the health of the nation (Poindexter, 1981).

Employment opportunities for disabled persons have been a primary focus of the vocational rehabilitation system (VR) since its inception. It was not until the mid fifties that vocational and employment services for the mentally retarded and other seriously disabled individuals were provdied through the VR system. The focus upon employment opportunities for the most severely disabled person was identified through the passage of P.L. 95-602, the Comprehensive Rehabilitation Services and Developmental Disabilities Legislation (Kiernan, 1979).

The trend towards recognizing both the importance of work to the individual and the capacities of even the most severely disabled has become much more established during the past decade (Schalock, 1983; Horner & Bellamy, 1979). Expansion of the opportunities to engage in meaningful work; and the development of strategies to train and support the developmentally disabled worker, served to further reinforce the viability of an employment goal for many disabled persons (Wehman, 1981; Bellamy, Horner, & Inman, 1979).

The use of time limited transitional employment programs, such as the Supported Work Program of the Bay State Skills Corporation (BSSC) in Boston, and the continual expansion of supported employment opportunities, as in the case of the Specialized Training Program (STP) model in Eugene, Oregon, show that both training and support play an important role in facilitating entry into employment for adults with developmental disabilities (Kiernan & Stark, in press; Ballis et al., 1984; Bellamy, Horner, & Inman, 1979). Many states have modified their approach in responding to the employment potential of the adult with developmental disabilities by establishing supported employment, enclave, work crew, and transitional employment options (Schalock, 1983). Although specific employment disincentives remain for the adult with developmental disabilities from both a fiscal and health care perspective, efforts to modify these policies, regulations, and legislation are underway (Conley, Noble, & Elder, in press). Extension of sections 1619 (a) and (b) of the Social Security Regulations is one attempt to minimize the economic and health care disincentives within the existing public support systems when considering employment of adults with developmental disabilities. Special provisions identified in studies such as the "Social Security Transitional Employment Demonstration Project," developing time limited training programs for mentally retarded SSI recipients, attempt to further minimize the risk of loss of benefits for disabled persons participating in this work training project.

Earlier efforts in providing training and employment services are now being viewed by many as limiting the opportunities for adults with developmental disabilities to gain greater degrees of economic self sufficiency (Wehman, 1983). A report published in 1981 by the U.S. Department of Health and Human Services reported that the average earnings of an individual in sheltered employment was about 35 percent of the minimum wage at that time. Earnings during that period for mentally retarded workers, the largest disability group served by the sheltered employment system, were only $417 per year per worker. Other reports (Karan, 1978; Rusch & Mithaugh, 1980) have indicated that individual productivity and movement into competitive employment for the disabled worker are not sufficiently enhanced in a sheltered employment environment. Proponents of options such as supported and transitional employment suggest that a natural work environment is a more desirable work training environment for even the most severely disabled workers (Horner & Bellamy, 1979; Ballis et al., 1984; Riccio & Price, 1984).

The following survey results serve to confirm other data showing that the move to a competitive employment setting for the adult with developmental disabilities is both realistic and financially sound (Hill & Wehman, 1983). While the survey response does not reflect data and results from every facility, the sample obtained is large enough to suggest that employment leading to an increased degree of economic self sufficiency is a viable goal for many adults with developmental disabilities.

II. Survey Procedures

Sample Selection Process

The Developmental Evaluation Clinic, a University Affiliated Facility located at Boston Children's Hospital, developed a survey instrument for the purpose of identifying and documenting the movement of adults with developmental disabilities into employment during the twelve month period from October 1, 1983 to September 30, 1984. The survey was prepared under a grant from the Administration on Developmental Disabilities. A list of rehabilitation facilities was compiled from mailing lists made available to the clinic by the National Association of Rehabilitation Facilities (NARF), the Administration on Developmental Disabilities (ADD) and various other directories.

Through this procedure, a total of 1,629 rehabilitation facilities, agencies, organizations and programs was identified throughout the fifty states as well as the District of Columbia, Puerto Rico, the Virgin Islands, and American Samoa. These programs were included in the survey because of their past involvement in providing vocational services to disabled persons. Table 1 shows the number of facilities by state which were included in the survey sample.

The total of those facilities included in the survey sample is considerably smaller than the 4,000 identified sheltered workshops which provide evaluation, training, employment, and other rehabilitation services noted in the Final Report on Training and Employment Services for Handicapped Individuals in Sheltered Workshops (Whitehead, 1981). This report stated that about 200,000 severely handicapped persons were served daily. This estimate is consistent with that made from the present data if all facilities in the survey had responded. The total number of persons with developmental disabilities receiving vocational services would be projected to be 185,000.

The discrepancy, with regard to the number of facilities surveyed in comparison to those noted by Whitehead (1981), may be explained by examining the facility identification procedures used in the Whitehead study. The number identified in that study reflected the total number of sheltered workshop certificates issued or on record in 1979 by the U.S. Department of Labor, Minimum Wage Division. All programs and agencies are required to have a workshop certificate for each of its branches or locations. Thus, those programs which had satellite or multiple sites may in fact have been recorded in the data base as many times as there were separate locations. Additionally, several small agencies or groups may maintain a labor certificate but in fact have no ongoing program.

The current survey sample, on the other hand, reflects the list of those agencies which have been identified within each state as providing employment and training services to disabled persons by the National Association of Rehabilitation Facilities and its affiliates as well as those agencies known to the Administration on Developmental Disabilities as providing vocational services to adults with developmental disabilities. Due to the nature of the various Projects With Industry programs, most of these were not included in this survey (approximately 12 percent of the total number of PWI's were sampled). The current survey sample, therefore, reflects an unduplicated representation of the key agencies, organizations, and programs known to provide employment and placement services to adults with developmental disabilities.

Survey Process Utilized

Each agency or organization on the list was sent an initial letter and a survey (see appendix). Included with the survey was a brief list of definitions to guide the respondents in interpreting the terms "developmental disabilities", "competitive employment", and "sheltered employment". Respondents were asked to provide information about the number of adults with developmental disabilities placed in both competitive and sheltered employment for the survey period (October 1, 1983 to September 30, 1984), as well as data on those entering competitive employment during the previous twelve month period (October 1, 1982 to September 30, 1983).

Optional questions included data on the average age of the individual at the time of placement, age ranges of those placed, average wages earned per hour, average number of hours worked per week, and the list of the occupational titles for the jobs obtained.

The survey procedures included establishing a subset consisting of every other facility from the master list which would be scheduled to receive a second letter. Ten days after the first survey was mailed, the facilities which had not already responded were sent a second survey and a second letter. Finally every fourth facility from the list of those receiving a second request was identified and contacted by telephone if a response had not been received from the second request. The contact was structured so that the purpose of the survey could be explained and the respondent could either provide the data over the phone or mail in their original survey form.

It was felt that by utilizing the three contact procedures, the potential number of respondents the survey would increase. The maximum number facilities or agencies to be contacted during ea phase of the survey procedure was:

— 1,629 receiving first mailing,
— 815 facilities receiving a second mailing,
— 205 facilities being contacted by telephone.

The established procedure reflects previo reported experiences with survey research and t strategies that have proven successful in increasi response rates.

III. Results

A total of 512 facilities, agencies and programs responded to the survey. Table 1 lists the facilities included in the survey state by state and territory. An analysis of the number responding is included in Table 2. The rate of response for the total sample was 31.4 percent. The distribution of responses throughout the nation was sufficiently representative such that the findings reflect minimal geographic bias.

Characteristics of Responding Facilities

As noted in Table 2, the rate of response reflects a broad geographic distribution. The size of facilities responding was also examined. Facility size was reflected by the total number of disabled persons served. The average number of disabled persons served per facility responding was 189. Due to a few extremely large facilities, the use of the mean as reflective of facility size is somewhat misleading. When facilities were grouped by the number of disabled persons served using increments of 25 persons (see Table 3), 75 percent of those facilities responding reported serving less than 200 disabled persons. The largest number of facilities (a total of 90 respondents), reported serving 26 to 50 disabled people. A total of 65 facilities or 13 percent served more than 300 and 1 percent or 6 facilities provide vocational services to 900 or more disabled persons. Considering the total number of disabled persons served by size of facility, the facilities which serve 200 or fewer disabled persons, provide vocational services to about one third or 31.4 percent of the total disabled population. The larger facilities while representing about 25 percent of those responding, provided vocational services to a greater proportion of the total number of disabled persons reported in the survey.

Number of Persons Served

In an effort to compare the percent of adults with developmental disabilities served with other disabled persons, respondents were asked to report the number of persons receiving vocational services meeting the functional definition of developmental disabilities. An analysis of the aggregate response (N = 512 facilities responding) shows that a total of 96,823 disabled persons received vocational services during the survey period (October 1, 1983 to September 30, 1984) and of this number, 58.2 percent or 56,334 persons were reported to be developmentally disabled (see Table 4).

Employment Status of Adults With Developmental Disabilities

Data reporting the number of adults with developmental disabilities who were placed in full and part-time competitive or sheltered employment is presented in Table 5. Of the total number of adults with developmental disabilities receiving vocational services 34,593, or 61.4 percent did not exit to either competitive or sheltered employment during the survey period.

An examination of those reported exiting to sheltered employment (n = 14,666), shows that 26 percent of the total number served entered sheltered employment. 10,434 persons or 18.5 percent of the total entered full-time sheltered employment, while 7.5 percent or 4,232 persons were placed in part-time sheltered employment. In comparing these findings with those adults who entered competitive employment, a total of 7,075 persons or 12.6 percent of the total population served during this period went into competitive employment. 5,122 persons or 9.1 percent of the total population entered full-time competitive employment, while 3.5 percent entered part-time competitive employment.

Employment Retention

Whereas job retention must be viewed within the context of a successful placement into employment, facilities were asked to report how many of those persons placed in competitive employment on both a full and part-time basis remained for more than 60 days.

Of those placed in both full and part-time competitive employment during the survey period, 75.9 percent remained on the job for at least sixty days. The retention rate for those in part-time competitive employment was reported to be 74.2 percent and 76.5 percent for those placed in full-time competitive employment (see Table 6).

Changes and Placement From Previous Year

As previously noted there appears to be an increasing tendency to move persons with developmental disabilities into competitive and supported employment, including such options as enclaves, work crews, and other employment activities in industrial settings. Facilities were asked to report the number of persons with developmental disabilities placed in the previous twelve month period. 5,028 persons entered full or part-time competitive employment in the previous twelve month period (October 1, 1982 — September 30, 1983), while 7,075 persons were reported entering full and part-time competitive employment during the survey period. This resulted in an increase of 40.7 percent in total placement for the survey period over the previous twelve month period (see Table 7). Viewed separately, the data reveals a 67 percent increase in the number of persons placed in part-time employment, and a 32.7 percent increase in the number of people placed in full-time employment over the previous twelve month period.

Characteristics of the Population Reported

Three optional questions regarding information on age, earnings and types of jobs were included in the survey. 81 percent of the total respondents completed the optional portion of the survey.

Age Distribution

There are some differences in the mean age of those adults with developmental disabilities entering sheltered employment as compared to those entering competitive employment (see Table 8). The mean age of the competitively employed adult was reported to be 27 years, four years younger than those placed in sheltered employment (31 years of age). The difference in the age range for the two groups was less; the maximum age for those placed in sheltered employment was reported to be three years older than for those placed in competitive employment.

Estimated Earnings through Competitive Employment

Average wage per hour and average hours worked per week in both part and full-time competitive employment were examined. Weekly, monthly and annual gross earnings were projected (see Table 9). There was an 8 percent difference in the hourly rate earned by those working part-time ($3.46 per hour) as opposed to those working full-time ($3.74 per hour). Coupled with the difference in hours worked per week, the annual projected income for those working part-time in competitive employment was $3,392 while those in full-time competitive employment earned more than twice this amount, $7,333 estimated annual income. As will be presented in the discussion section, the benefits and costs to those in full-time competitive employment differ from those entering part-time competitive employment.

Types of Employment Obtained

The types of employment obtained by 5,844 adults with developmental disabilities are presented in Tables 10 and 11. Although nearly one-third are in the janitorial area and a total of 72 percent are either janitorial, assembly, or food services, more than 11 percent enter jobs which could be viewed as less traditional for adults with developmental disabilities. This data illustrates that placement for such persons can include a wide variety of occupational titles and job activities. Whereas some of these jobs recorded in Table 11 appear to reflect the uniqueness of the area, it does show that with certain degrees of creativity, adults with developmental disabilities can meet the challenge of many different types of jobs.

State by State Presentation of Survey Data

Though the presentation of the data in this survey reflects aggregate analysis, it would be of interest to some readers to present individual state and territory responses (see Table 12). The data is presented in an aggregate fashion with the numbers reflecting a total of all facilities responding from that state. The number in the parenthesis next to the name of the state indicates the number of facilities from that state which responded to the survey.

The data presented reflects the total number of disabled persons receiving vocational services, the number of persons with developmental disabilities receiving vocational services, the number of persons with developmental disabilities entering full and part time competitive and sheltered employment, the number remaining in competitive employment for more than sixty days (employment retention), and finally, the number of persons with developmental disabilities entering competitive employment during the previous twelve month period.

The state by state data parallels the above presented study findings. Though no specific trends emerged in the state by state analysis of the data, the reader may wish to compare his/her specific state with others as well as with the overall findings of this survey.

IV. Discussion

A number of specific elements from the current study merit further consideration. Issues such as the placement rate of adults with developmental disabilities into competitive employment, the continuing focus upon placement into sheltered employment, the concerns relating to employment retention, and the estimated benefits and costs to entering full or part-time competitive employment for the individual and society are further explored. The discussion section examines each of these separately presenting further interpretations of the data obtained and its implications for the future.

Placement Rate

The survey results showing a greater than 40 percent increase in the actual number of adults with developmental disabilities placed in either part-time or full-time competitive employment over the previous twelve month period is extremely significant. However, due to the limitations in the survey design and data collection procedures, it is not possible to know if the placement rate of 12.6 percent (3.5 percent in competitive part time, and 9.1 percent in competitive full-time) for the survey period is different than the placement rate of the previous twelve month period. An earlier report (Whitehead, 1981) noted that about 8 percent of all disabled persons served by facilities were entering competitive employment in 1979. The 12.6 percent placement rate for the current survey reflects a 57 percent increase in the placement rate over that indicated in the Whitehead report. The authors note that when interpreting this 8 percent figure other individuals who are not developmentally disabled are most likely included. The present study however, reflects a placement rate of adults with developmental disabilities only. The percentage of increase therefore may be even greater than the 57 percent figure reported here. From the above analysis, it can be concluded that the activity of placing adults with developmental disabilities into employment is clearly increasing.

Placement In Sheltered Employment

Although there is an increase in the number of adults with developmental disabilities who are being placed in full and part-time competitive employment, the data from the current survey shows that the placement rate into sheltered employment is more than twice the rate (26 percent) of those entering competitive employment. More than two out of every three adults with developmental disabilities who exit a program or facility are placed into sheltered employment. These findings are consistent with much of the data reported in the literature in the past decade showing that the rate of placement in sheltered employment remains high in relationship to those who are placed into competitive employment.

This finding is troubling in light of some of the research and program activities showing that many adults with developmental disabilities can work at a competitive rate (Wehman, 1981 Paine, Bellamy, & Wilcox, 1983; Kiernan & Start, in press). Several examples of rehabilitation facilities providing vocational services utilizing work crew and enclave designs in industry are now being reported. Initiatives such as the expansion of the supported employment concepts have recognized that the use of the actual work setting rather than a sheltered environment is a more appropriate training and work environment for the adult with developmental disabilities (Will, 1984).

Major efforts on the part of service agencies, funding organizations, and industry are necessary if there is to be an increase in the placement rate of adults with developmental disabilities into a natural work environment. These efforts will require changes in funding patterns so that activities such as supported employment can be viewed as a fiscally viable service option for agencies, organizations, and facilities providing vocational services to the more severely disabled individual. Creative employment options and activities, such as work crews and enclaves, will need to be pursued more directly with industry. New views of the rehabilitation and industry partnership must be explored as advances in training and changes in production technology continue. The rapid growth in the number of service occupations calls for more aggressive training of adults with developmental disabilities so that entry into these occupational clusters may be possible.

Although there has been an increase in the number of persons with developmental disabilities placed in competitive jobs, placement in sheltered environments remains a more frequent outcome of the rehabilitation process. Continuing advances in approaches to training and service delivery are necessary if this trend is to be reversed. Closer working relationships between rehabilitation and industry can facilitate expansion of industry based training for the adult with developmental disabilities.

Employment Patterns/Job Mobility

The rate of employment retention (75.9 percent) identified in the present survey is consistent with the rate reported by other recent studies. The Baystate Skill Corporation (BSSC) in their two year follow-up (Bailis et al., 1984), reported a retention rate of 84 percent based upon a sample size of approximately 300 mentally retarded persons who participated in this statewide program. The final STETS demonstration report noted an 84 percent retention rate for mentally retarded adults participating in these various projects. The rate of job retention for Project Employability (PE) since the beginning of that project has been reported to be between 50 and 55 percent, (Hill & Wehman, 1983). Previous measures of that same project showed a retention rate of 66 percent (Wehman, 1982). As a result of a two year follow-up, a 70 percent retention rate of mentally retarded adults was reported by the Supported Work Project at Children's Hospital in Boston (Shefstakofsky, Van Gelder and Kiernan, in press).

Although the criteria of 60 days to measure successful placement reflects the current practices of the rehabilitation system, it is, in the authors' opinion, not sufficient to validly measure employment retention for many workers with development disabilities. Recent studies have indicated that adults with developmental disabilities may encounter employment retention difficulties beyond the initial two month period (Bailis et al., 1984; Riccio & Price, 1984; Hill & Wehman, 1983). Problems related to job duty changes, supervisory and personnel changes, and interpersonal difficulties on the job, in addition to technological advances, have been related to production difficulties and termination for some adults with developmental disabilities on the job. An additional length of time to monitor employment retention is essential if a true estimate of permanency in employment for adults with developmental disabilities is to be established.

Employment retention should be viewed as only part of the adjustment of the individual to the job. In addition to assisting the adult with developmental disabilities in maintaining a job, it is also important to assist that individual in increasing his/her degree of economic self sufficiency through promotion in the employment world. While there is a desire to secure a stable and long term job for the adult with developmental disabilities, job changes do occur and a certain degree of job mobility is healthy. Measures of frequency of job change and improvement in employment status as a result of job change need to be developed. Absence of mobility can frequently limit increases in earning for the individual and may lead to boredom for that individual on the job. To evaluate the success of the rehabilitation effort for adults with developmental disabilities solely on placement status, ignores the fact that there is a degree of career mobility for all individuals. If a system is to be responsive to career changes, then there is the need to develop a mechanism which can assist both the adult with developmental disabilities and industry in enhancing career ladder opportunities leading to increased levels of independence and continued job satisfaction for the worker.

Estimated Benefits and Costs

In an attempt to present a true picture of the benefits and costs to both the individual who is developmentally disabled and to society some projections regarding the total number of adults with developmental disabilities placed by all facilities, organizations, and programs must be made. To assure that those not responding to the survey were to some extent equivalent to the group that responded, a random check of non-respondents was made by telephone. Inquiries as to the nature of the services offered and the type of persons served revealed a great deal of consistency among the facilities within the entire survey sample. A total of 200 facilities or about 18 percent of those not responding were contacted or material regarding the program on file with the Administration on Developmental Disabilities was examined to determine consistency among the respondent and non respondent groups. The results of this process allowed the authors to project total numbers of persons served, had all facilities responded. Utilizing a 31.4 percent response rate, it was projected that a total of 22,510 adults with developmental disabilities were placed by all 1,629 facilities during the survey period; 16,297 developmentally disabled adults entered part time employment. Estimates of hours worked, wages paid, and rates of retention on the job were assumed to be consistent with those actually reported in the survey. The population estimates were utilized to develop projections of total benefits and costs for society associated with the employment activities during a one year period. The analysis of the benefits and costs to employment for the individual adult with developmental disabilities, however, reflects a review of the specific data reported in the survey.

Qualities of a Benefit Cost Analysis

Questions of cost and benefit are becoming more frequently asked in human services. Benefit/cost analysis is a method of responding to these inquiries. Typically, the cost calculations in such an analysis are straightforward. The difficult part of the analysis is estimating the value of the benefits (Anthony & Reece, 1975). In many situations, meaningful estimates of the actual cash amount of the benefits cannot be made. Subjective estimates of the value of elements such as the quality of life the quality of work life, personal and/or family well being, and psychological/attitudinal gains must be made if a comprehensive benefit/cost analysis is to be undertaken (Schalock & Hill, in press). A much more extensive documentation of return to the individual in the various areas would need to be undertaken. For purposes of this present study, no estimates of the value of these gains, however, have been made.

Those more measurable and quantifiable elements of the benefits and costs which relate to the movement of adults with developmental disabilities into employment can be examined. Typically, the benefits and costs are interpreted in light of the impact upon the individual and society. In some instances the benefits and cost for society are separated out into those which have a net yield for the taxpayer and those which have a net yield for society as a whole. The former tends to look at actual cash contributions through taxes and decreases in publicly sponsored program costs, while the latter looks at increases in the money supply or available monies that an individual may have due to earnings as well as the savings in alternative publicly sponsored program costs. The present analysis will look at the contribution to society as a combination of net yield to the taxpayer and society in general.

The development of a benefit/cost analysis does not pass judgement upon the program or activity but rather provides data to assist in evaluating contributions made by a program or activity while serving to develop a more refined strategic planning process (Riccio and Price, 1984). The results presented below therefore, should be viewed as data to assist in planning for the future rather than a critique of past activities.

From society's perspective, the benefits resulting from the increasing number of adults with developmental disabilities entering employment include individual and industry tax contributions, the reduction in transfer payments to the individual, and a decrease in cost associated with alternative publically supported day programs. An analysis of these variables is based upon 16,297 adults with developmental disabilities placed in full-time competitive employment and 6,213 placed in part-time competitive employment. Assuming that the average earnings per hour and hours worked per week would be consistent with the data received in the survey, estimates of gross income for the total sample after adjusting for employment retention would be about 107 million dollars (see Table 13).

Individual Tax and Social Security Adjustments

To calculate net earnings per person, adjustments for state and federal taxes and the social security contribution were made. These calculations show that the net earnings per worker in full-time competitive employment are $6,056 annually (see Table 14). The net annual earnings per worker in part-time competitive employment are $3,092 (see Table 15). The tax and social security contribution from the individual in full-time competitive employment is $1,277 and $300 for part-time. This contribution reflects estimates of state and federal income tax and individual social security contributions on earnings. The calculations are based upon the guidelines utilized by the Internal Revenue Service and the median projected tax obligations at a state level. This procedure was chosen over the estimated rate of 23 percent of gross income for low wage workers (Pechman & Okner, 1974), to more accurately reflect the tax contributions of the part-time worker. In utilizing the guidelines from the IRS and the estimated average state tax, the actual tax contribution is projected in a somewhat more conservative fashion. As in all of the benefit/cost estimates, a conservative approach was utilized.

Tax and Social Security Contributions Estimated for Total Sample

In order to examine the total tax contributions resulting from employment, adjustments for retention must be made. 76.5 percent of those placed in full-time competitive employment were projected to remain on the job for more than 60 days while 74.2 percent would remain in their part-time placements for more than sixty days. Adjusting for job turnover, total tax contributions for the full estimated sample of adults with developmental disabilities placed is in excess of 22.7 million dollars annually (see Table 16). To more fully represent society's return on its investment, that portion of the social security contributions made by industry should be included. This would bring the total direct and indirect contribution attributable to adults with developmental disabilities who enter employment during the survey period to more than 30 million dollars annually (see Table 16).

In addition to the taxes which society will receive as a result of earnings, savings by reductions in transfer payments and savings in costs for alternative publicly supported programs must be considered. This latter saving reflects a reduction in costs associated with maintaining an individual in a day program or some other type of comparable program if that person is not in competitive employment.

Reduction in Transfer Payments

The savings realized from a reduction of transfer payments must be estimated since specific data on the number of individuals receiving some form of public support (e.g. SSI, SSDI, general relief, etc.), and the amount of that support were not collected as part of this survey effort. The savings in this area, however, are anticipated to be substantial and must be considered as a benefit to society. Prior studies dealing with similar populations have shown that about 70 to 75 percent of those in training and placement programs receive some type of support (Bailis et al, 1984; Riccio & Price, 1984; Hill & Wehman, 1983). In the vast majority of the cases, this support is in the form of federal and state cash payments (e.g. SSI).

Data reported by Mathematica Policy Research (Thorton, 1984), noted that the average SSI payment in December of 1983 was $245 per month. This figure does not include the elderly and blind who may receive SSI payments. The use of this figure would imply that most SSI recipients had either earned or unearned income which reduced their SSI payments from the maximum allowable amount. Taking into consideration the variations in state procedures regarding supplementation of SSI, it was felt that this figure could be considered as representative of the average SSI payment for those in the survey. It was also assumed that any earned income would reduce the estimated SSI payment by $1 for every $2 earned since the general exclusions from income had already been taken. Given these assumptions the average saving from transfer payments would be the total of SSI payment ($245 per month) for those beneficiaries employed full time. A savings of $141 dollars per month would be realized for those who are employed part time and receiving SSI.

Assuming 75 percent of adults with developmental disabilities reported in this survey received such payments, and adjusting for a rate of employment retention, a total savings of more than 33 million dollars per year in SSI payments can be anticipated (see Table 17).

Medicaid savings are much more difficult to calculate. Assuming that an individual who is eligible for SSI payment remains eligible for Medicaid, and taking into consideration the provisions of 1619 (b), then only those earning more than the average threshhold amount (about $12,500 annually) would be removed from Medicaid. According to data received, only 4 percent of adults with developmental disabilities in competitive work would make a monthly income in excess of the threshhold amount. Assuming also that 75 percent of this population is on Medicaid prior to entering employment, only 3 percent of those working full time or about 374 individuals would represent a savings in Medicaid payments to society.

The annual expenditure for Medicaid was reported by the Social Security Bulletin Annual Statistical Supplement, (U.S. Department of Health and Human Services, 1983), to be $1,357. The total annual savings therefore would be estimated to be only about $507,500.

Alternative Program Cost Savings

The last savings, the decrease in costs of alternative publicly supported programs, must also be viewed as an approximation. General estimates of sheltered employment and day habilitation program costs range from $2,500 to $10,000 or more per year. A conservative estimate of $4,160 dollars per year was chosen to reflect the average cost of this type of program. This reflects a $16 per day rate for either a day or sheltered workshop program. Adjusting for employment retention, a total of 18,574 persons remained in employment during the survey period. Assuming that those in both part and full time competitive employment are no longer involved in alternative day or sheltered workshop programs, this would reflect a savings of more than $71 million dollars (see Table 17).

The total return on investment realized by society is almost $135 million annually based upon 1984 dollars. The estimates on return to society do not include the multiplier effects due to enhanced net cash positions for those adults with developmental disabilities engaged in competitive full or part time employment.

The purpose of this analysis, as well as, a review of the individual returns is not to be a precise measure of economic gain but rather to show trends in employment activities. The estimate of the benefits yielded to society reflects assumptions which may be debated. Clearly what can not be debated is that society realizes considerable benefit when adults with developmental disabilities enter and remain in competitive employment.

Benefit and Cost to the Individual

Individuals as well as society must benefit if employment is to continue to be a realistic and desirable goal for adults with developmental disabilities. The net benefit to the individual is not only monetary, but includes the personal, emotional, and social gains derived from the job. Although these gains are qualitative in nature and extremely difficult to measure, their impact is significant and they frequently play a major role in job retention.

The changes in the net cash position for the individual, on the other hand, are quite measurable. These changes reflect the additional amount of cash or disposable income that the individual has in light of his or her earnings through employment when compared to all previous sources of income. In calculating such a figure, estimates of changes in transfer payments must be made. For society, the reduction in transfer payments is an asset; for the individual it is a liability. The changes in net cash position for the person employed full time on SSI is approximately $3,116 annually (see Table 14). This figure represents adjustments of the gross income due to taxes and the elimination of any transfer payment revenue in light of the individual's employment activities. For the part time worker the change in net cash position is $1,400 (see Table 15). This figure reflects the adjustment of gross income due to taxes as well as the inclusion of the remaining amount of transfer payments for which the person is entitled (a total of $104 per month).

The figures above present the picture of an adult with developmental disabilities who is receiving the estimated average SSI benefits for December 1983. Obviously for those receiving a lower benefit level or no benefits, the net gain from earnings is considerably greater and for those receiving higher benefits the net gain will be less.

The data does not address issues related to Medicaid benefits and the potential added expenses for those individuals who may lose their benefits. This issue may be significant for those adults with developmental disabilities as they enter employment at above the threshhold level. The passage of the extension of 1619 (b), however, has considerably reduced the risk of losing Medicaid when entering employment for most adults with developmental disabilities.

A figure not calculated into the net cash position is the loss of earnings for those who may have been employed in a sheltered workshop. This must be viewed as a loss to an individual and thus reduce the economic gain to entering employment for that individual. As will be seen in the following section, this loss in income could be about $817 per year on the average. However, when adjusting for this loss it is clear that the net cash position for both part and full time employment continues to remain positive for the adult with developmental disabilities.

A Comparison of Sheltered and Competitive Employment

In light of the above noted placement rates into competitive and sheltered employment, a brief look at the two outcomes would be appropriate. No data on earnings in sheltered employment was requested by the current survey, however, prior reports have shown that sheltered employment earnings are lower than the estimated changes in net cash position for the adult with developmental disabilities who is in either part or full time competitive employment. Using as a base the figure reported for annual income ($414) in the National Survey of Sheltered Workshops in 1976 (Schlock, 1983), and adjusting this to reflect 1983 dollars, the estimated earnings in sheltered employment would be $817 annually.

(Adjustment based on annual reported earnings in 1976 ($414) and consideration of an average 9 percent annual adjustment for inflation and wage rate modification for an eight year period compounded.)

The projected annual earnings through sheltered employment are less than one-fourth of the gross earnings of those in part time competitive employment and about nine times less than the gross earnings for those in full time competitive employment. It must also be noted that there is considerably less benefit to society when the adult with developmental disabilities remains in sheltered employment. There is minimal reduction in the cost to society since there needs to be a continuation on a daily basis of the fiscal support for the services rendered by day programs or sheltered workshops. This cost is supported by society and the taxpayer directly. There are also fewer savings due to a higher rate of transfer payments for those in sheltered work programs than for those in either part or full-time competitive employment. Thus, many of the gains to society realized by those entering competitive employment are not present when the individual remains in sheltered employment.

V. Conclusions

To present the data from this study as irrefutable would be inappropriate. A number of study limitations including the obvious bias in self reporting must be kept in mind when reviewing the results. The many assumptions with regard to the estimates of the total number placed by all facilities in the survey, the use of the average number to reflect wages and other data reported, and the assumptions associated with benefits/cost serves to remind the reader that the results must be viewed not as a definitive analysis of placement and the benefits and costs of having adults with developmental disabilities enter competitive employment, but only as an indication that the yield for both the individual and society is significant when competitive employment is the outcome of the rehabilitation process.

Acknowledging the limitations of the present study does not eliminate the possibility of drawing some conclusions and making some observations based upon the data reported. The trend toward a greater economic yield for the individual and society when the adult with developmental disabilities enters competitive employment should reaffirm the efforts of those agencies, facilities, and organizations which are seeking to expand the industrial environments within which employment and increased levels of economic self sufficiency can be realized.

There is a need to more accurately document both the movement of adults with developmental disabilities into employment and the benefits and costs attributable to the individual and society. The current study results would imply that there is a substantial advantage to the individual and society. However, a more precise documentation of this and a measurement of the magnitude of the advantage is necessary.

Specific policy and administrative changes would be viewed as supportive of the efforts to assist the adult with developmental disabilities in entering employment. The emphasis upon supported employment will allow those more disabled to access an industrial work environment and enhance the degree of economic self sufficiency realized by these individuals. The adoption of the Social Security provisions (1619 (a) and (b)) needs to be considered on a more permanent basis if the economic disincentives towards competitive employment are to be dealt with.

These efforts will encourage facilities, individuals with developmental disabilities , and families to consider other options such as supported or competitive employment as viable goals. Permanent support and ongoing medical coverage will allow the placement of more severely disabled persons into supported and competitive employment environments.

Special attention will also need to be given to the issue of employment retention and job mobility. Supports provided in a timely fashion may avoid job failure in some instances and assist others to move to higher paying positions. Placement for many adults with developmental disabilities cannot be viewed as the end of the rehabilitation process. Assistance at various transition points may be necessary if the individual is to maintain an employment status. There is a need to have a timely and efficient system to respond to the individual who is employed but may require intermittent assistance to maintain employment.

Though not examined in the present survey, a look at the fringe benefits which are associated with the jobs obtained by adults with developmental disabilities is necessary. In many instances due to the entry level nature of the jobs and the type and size of the industry, few fringe benefits, if any, are provided. An examination of the benefits received would provide data regarding the needs for support through alternative sources (e.g. 1619 (a) and (b)) as the adult with developmental disabilities enters employment.

The results of the present survey must be viewed not as a complete analysis of employment for adults with developmental disabilities but a reflection of the trends in employment. There has been an increase in the number of persons placed during the survey period, various career clusters are being accessed by adults with developmental disabilities, and on average the benefits and costs for both the individual and society are positive. The role of the adult with developmental disabilities in employment is expanding and the movement into competitive employment is a reasonable, appropriate, and viable goal for this population of persons.

TABLE 1

Number of Facilities Included in Survey Sample by State and Territory

	# Sent		# Sent		# Sent		# Sent
Alabama	20	Missouri	27	Illinois	66	Rhode Island	10
Alaska	9	Montana	10	Indiana	54	South Carolina	9
American Samoa	1	Nebraska	17	Iowa	23	South Dakota	5
Arizona	21	Nevada	7	Kansas	34	Tennessee	34
Arkansas	15	New Hampshire	9	Kentucky	20	Texas	47
California	174	New Jersey	38	Louisiana	10	Utah	4
Colorado	25	New Mexico	14	Maine	10	Vermont	5
Connecticut	41	New York	108	Maryland	27	Virgin Islands	1
Delaware	7	North Carolina	27	Massachusetts	45	Virginia	73
District of Columbia	12	North Dakota	2	Michigan	50	Washington	65
Florida	64	Ohio	43	Minnesota	28	West Virginia	21
Georgia	57	Oklahoma	9	Mississippi	29	Wisconsin	53
Hawaii	6	Oregon	36			Wyoming	5
Idaho	8	Pennsylvania	92				
		Puerto Rico	2				

TOTAL: 1,629

TABLE 2

Number of Participating Programs Responding by State and Territory

	# Sent	# Rec'd	Rate Ret'd		# Sent	# Rec'd	Rate Ret'd
Alabama	20	4	20%	Nebraska	17	4	24%
Alaska	9	1	11	Nevada	7	2	29
American Samoa	1	1	100	New Hampshire	9	5	56
Arizona	21	10	48	New Jersey	38	13	34
Arkansas	15	7	47	New Mexico	14	6	43
California	174	51	29	New York	108	46	43
Colorado	25	4	16	North Carolina	27	10	37
Connecticut	41	19	46	North Dakota	2	2	100
Delaware	7	1	14	Ohio	43	12	28
District of Columbia	12	2	17	Oklahoma	9	2	22
Florida	64	23	36	Oregon	36	13	36
Georgia	57	13	23	Pennsylvania	92	24	26
Hawaii	6	1	17	Puerto Rico	2	0	0
Idaho	8	2	25	Rhode Island	10	2	20
Illinois	66	20	30	South Carolina	9	11	122
Indiana	54	9	17	South Dakota	5	2	40
Iowa	23	11	48	Tennessee	34	10	29
Kansas	34	11	32	Texas	47	17	36
Kentucky	20	6	30	Utah	4	2	50
Louisiana	10	3	30	Vermont	5	3	60
Maine	10	6	60	Virgin Islands	1	0	0
Maryland	27	7	26	Virginia	73	20	27
Massachusetts	45	20	44	Washington	65	18	28
Michigan	50	13	26	West Virginia	21	7	33
Minnesota	28	4	14	Wisconsin	53	17	32
Mississippi	29	6	21	Wyoming	5	1	20
Missouri	27	6	22				
Montana	10	2	20	TOTAL:	1,629	512	——

TABLE 3

Characteristics of Responding Facilities Grouped by Number of Disabled Adults Served (n = 96,823)

Size of Facility	Total Number of Disabled Adults Receiving Services	Number of Facilities Reporting	Cumulative Percent of Facilities Reporting
1 - 25	636	44	9%
26 - 50	3,425	90	28
51 - 75	3,102	49	38
76 - 100	3,915	45	47
101 - 125	4,840	43	56
126 - 150	5,614	40	65
151 - 175	4,892	30	71
176 - 200	4,008	21	75
201 - 225	3,631	17	78
226 - 250	4,052	17	82
251 - 275	2,394	9	84
276 - 300	4,627	16	87
301 +	51,687	65	100
TOTAL:	96,823	486*	

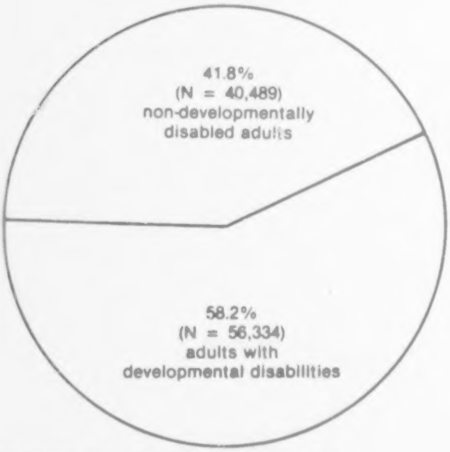
* 26 respondents reported not providing vocational services

TABLE 4

Number of Adults with Developmental Disabilities Compared to All Disabled Persons Receiving Vocational Services

October 1, 1983 - September 30, 1984

Total Number Receiving
Vocational Services
(N = 96,823*)



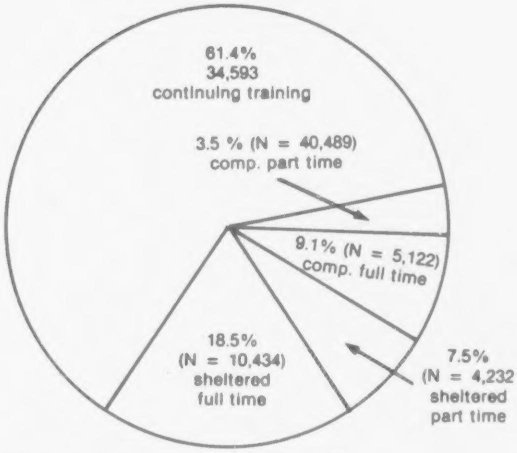
* Data based upon 512 facilities responding

TABLE 5

Training and Placement Status of Adults with Developmental Disabilities

October 1, 1983 - September 30, 1984

Total Number of Adults
With Developmental Disabilities
(N = 56,334*)



* Data based upon 512 facilities responding

TABLE 6

Employment Retention After 60 Days

Total Number of Adults
With Developmental Disabilities
Placed in Competitive Employment
(N = 7,075)

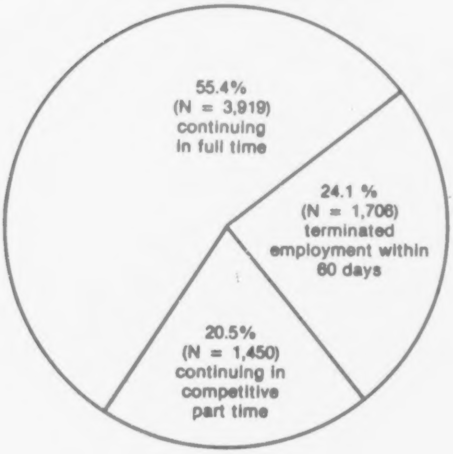


TABLE 7

Comparison of Adults with Developmental Disabilities Entering Employment In Survey Period to Those Entering Employment In Previous Twelve Month Period

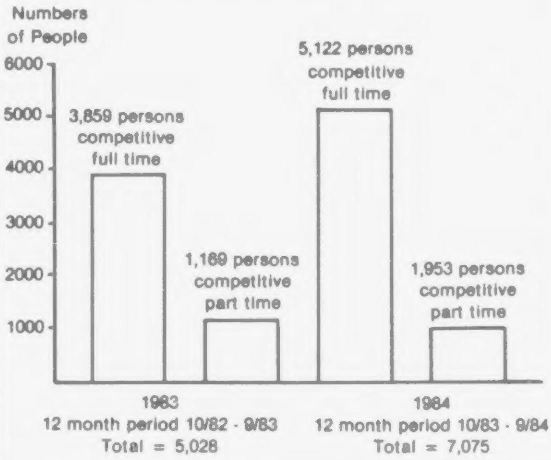


TABLE 8

Age Characteristics of Adults with Developmental Disabilities

Average Age and Age Range
(at the Time of Placement)*

	Mean Age	Range
Competitive Employment (N = 5,684)	27	19 - 39 years
Sheltered Employment (N = 10,461)	31	19 - 42 years

* Data reflects 94 percent of total population with adjustments excluding top and bottom 3 percent of sample.

TABLE 9
Wages Earned and Hours Worked by Adults with Developmental Disabilities in Competitive Employment

A. Average Wage Paid in Competitive Employment
(at Time of Placement)

Full time	$3.74	N = 4,158
Part Time	$3.46	N = 1,665

B. Average Hours Worked (Per Week at Time of Placement)

Full time	38 hrs/wk	N = 4,067
Part time	19 hrs/wk	N = 1,612

C. Estimated Gross Earnings (In Competitive Employment)

	weekly	monthly	annually
Full time	$142.12	$611.12	$7,333.39
Part time	65.74	$282.68	$3,392.18

TABLE 10

Types of Employment by Occupational Title

	Total Number	Percent of Total
Janitorial/Cleaning/Maintenance	1,919	32.83%
Assembly	1,235	21.13%
Food Service/Preparation	1,074	18.38%
Clerical	466	7.97%
Dish Maching Operator	326	5.59%
Delivery	166	2.84%
Other*	658	11.26%
TOTAL:	5,844	100.00

* See Table 11 for representative list of job titles

TABLE 11

Selected Occupational Titles In "Other Occupational Category"

Pallet Builder
Computer Programmer
Construction Firm—Helper
Mechanic's Assistant
Landscaper
Transportation Aide
Utility Worker
Shipper/Receiver
Carnival Assistant
Childcare Worker
Farm Laborer
Printer
Nursing
Veterinarian Assistant
Tax Examiner
Dock Worker
Gas Station Attendant
Shoe Repair
Furniture Refinisher
Security Guard
Recycling Equipment Worker
Lab Assistant
Test Technician
Teacher's Aide
Fisherman
Cab Driver
Micro Film Technician
Live-in Assistant
Zoo Attendant
Fisheries Assistant
Junk Yard Worker
Cosmetologist
Recreation Aide
Day Care Worker

TABLE 12

Placement Data by State and Territory

State & Number of Returns	# of Adults with Disability Served	Total of Adults with Developmental Disabilities						
		Served	In Comp. Full Time	In Comp. Part Time	In Shel. Full Time	In Shel. Part Time	On Job more than 60 Days	Placed in Previous 12 Mos.
Alabama (4)	767	330	20	1	59	40	21	25
Alaska (1)	67	42	0	10	0	32	5	4
Arizona (10)	1327	1311	101	22	43	234	100	40
Arkansas (7)	651	444	74	33	56	2	73	57
California (51)	7276	5737	222	148	1018	877	228	280
Colorado (4)	413	202	1	6	9	4	4	6
Connecticut (19)	3278	2759	191	29	444	52	175	161
Delaware (1)	0	0	0	0	0	0	0	0
District of Columbia (2)	80	80	45	8	4	0	41	53
Florida (23)	2949	1738	136	40	89	247	137	137
Georgia (13)	1089	742	122	51	24	32	117	114
Hawaii (1)	450	310	15	0	24	0	12	10
Idaho (2)	360	200	16	2	9	0	16	5
Illinois (20)	3939	2852	288	132	136	81	370	289
Indiana (9)	2159	1754	90	27	523	23	84	88
Iowa (11)	1004	741	25	42	106	81	50	49
Kansas (11)	1536	1082	196	31	70	37	50	153
Kentucky (6)	232	217	16	19	3	50	33	8
Louisiana (3)	1230	446	65	15	23	0	64	68
Maine (6)	527	398	33	51	23	3	67	51
Maryland (7)	1328	833	90	37	9	85	109	74
Massachusetts (20)	3241	2256	474	73	447	119	453	354
Michigan (13)	1679	1202	36	38	174	73	65	29
Minnesota (4)	1451	1064	62	7	26	97	63	52
Mississippi (6)	691	611	48	0	51	251	38	68
Missouri (6)	173	112	7	12	17	0	19	20
Montana (2)	45	43	2	19	0	19	17	14
Nebraska (4)	196	196	2	10	4	2	11	5
Nevada (2)	359	355	34	1	211	26	31	26
New Hampshire (5)	191	123	18	5	66	18	19	9
New Jersey (13)	1819	1317	127	32	636	52	146	87
New Mexico (6)	1052	564	90	30	74	50	98	29
New York (46)	25958	9124	641	212	2674	140	628	714
North Carolina (10)	13847	2785	108	6	29	12	98	63
North Dakota (2)	177	177	26	11	23	0	30	18
Ohio (12)	1928	965	211	64	156	224	192	166
Oklahoma (2)	156	32	12	0	8	0	0	9
Oregon (13)	1225	1017	75	18	331	127	75	84
Pennsylvania (24)	4287	3385	427	204	499	40	521	487
Puerto Rico (0)	0	0	0	0	0	0	0	0
Rhode Island (2)	202	202	18	10	43	44	22	15
South Carolina (11)	1000	918	57	24	370	103	69	12
South Dakota (2)	295	207	18	5	5	0	22	11
Tennessee (10)	1024	901	46	7	86	136	47	33
Texas (17)	6135	2574	151	52	844	232	203	168
Utah (2)	797	393	99	9	44	80	94	136
Vermont (3)	40	40	9	18	0	0	24	27
Virgin Islands (1)	83	72	0	0	0	0	0	0
Virginia (20)	2149	1846	160	131	381	109	234	214
Washington (18)	3420	942	77	104	140	194	114	100
West Virginia (7)	348	225	16	6	48	8	15	4
Wisconsin (17)	2916	1756	193	106	349	131	244	252
Wyoming (1)	77	72	3	4	0	56	5	4

TABLE 13

Selected Occupational Titles In "Other Occupational Category"

Full Time

16,297	x	.765*	x	7,333.39	=	91,426,876
# of adults with D.D. in comp FT. employment	x	retention rate for 60 days for 60 days	x	est. annual gross earnings	=	total est. gross earnings FT. comp. employment

Part Time

6,213	x	.742	x	3,392.18	=	15,638,106
# of adults with D.D. in comp. PT. employment	x	retention rate for 60 days	x	est. annual gross earnings	=	total est. gross earnings PT. comp. employment

Total Gross Earnings $ 107,064,982
(Full and Part Time Employment)

*Adjusted for retention of 60 days
Full Time 76.5%
Part Time 74.2%

TABLE 14

Net Cash Position for the Adult with Developmental Disabilities (estimated)

Full Time Competitive Employment

A. Gain to the Individual		
1. Gross Earnings		$7,333
2. Less Tax Expenses		
— Federal Income Tax	512	
— State Income Tax	248	
— Social Security	517	
	1,277	(1,277)
Net Income from Employment		6,056
3. Social Security Payment * (0/month)		0
Total Net Income		6,056
B. Net Loss to the Individual		
Total Social Security Payment (245/month)*		(2,940)
Changes in Net Cash Position		$3,116

* average annual SSI payment
state and federal $245/mo. in December 1983

TABLE 15

Net Cash Position for the Adult with Developmental Disabilities (estimated)

Part Time Competitive Employment

A. Net Gain to Individual		
1. Gross Earnings		$3,392
2. Less Tax Expenses		
— Federal Income Tax	10	
— State Income Tax	51	
— Social Security	239	
	300	(300)
Total Net from Employment		3,092
3. Social Security Payment * (104/month)		1,248
Total Net Income		4,340
B. Net Loss to the Individual		
Total Social Security Payment ($245/month)*		(2,940)
Net Cash Position		$1,400

* average annual SSI payment
state and federal $245/mo. in December 1983

TABLE 16

Annual Tax Contributions by Estimated Full Sample of Adults with Developmental Disabilities Placed During Survey Period*

	Part Time	Full Time	Total
Federal Income Tax	$ 46,100	$6,383,104	
State Income Tax (Estimated)	235,110	3,091,816	
State Unemployment Tax (Avg. 4.5% up to $7,000)	703,670	3,927,105	
Federal Unemployment Tax (.8% up to $7,000)	125,097	698,152	
Soc. Sec. Ind. Contribution	1,101,790	6,445,439	
Tax Contribution by all employed individuals	2,211,767	20,545,616	
			$22,757,383
Soc. Sec. Business Contribution	1,101,790	6,445,439	
		Total Business Contribution	7,547,229
		Total Tax Contribution	$30,304,612

*16,297 x .765 Retention rate = 12,467
6,213 x 742 Retention rate = 4,610

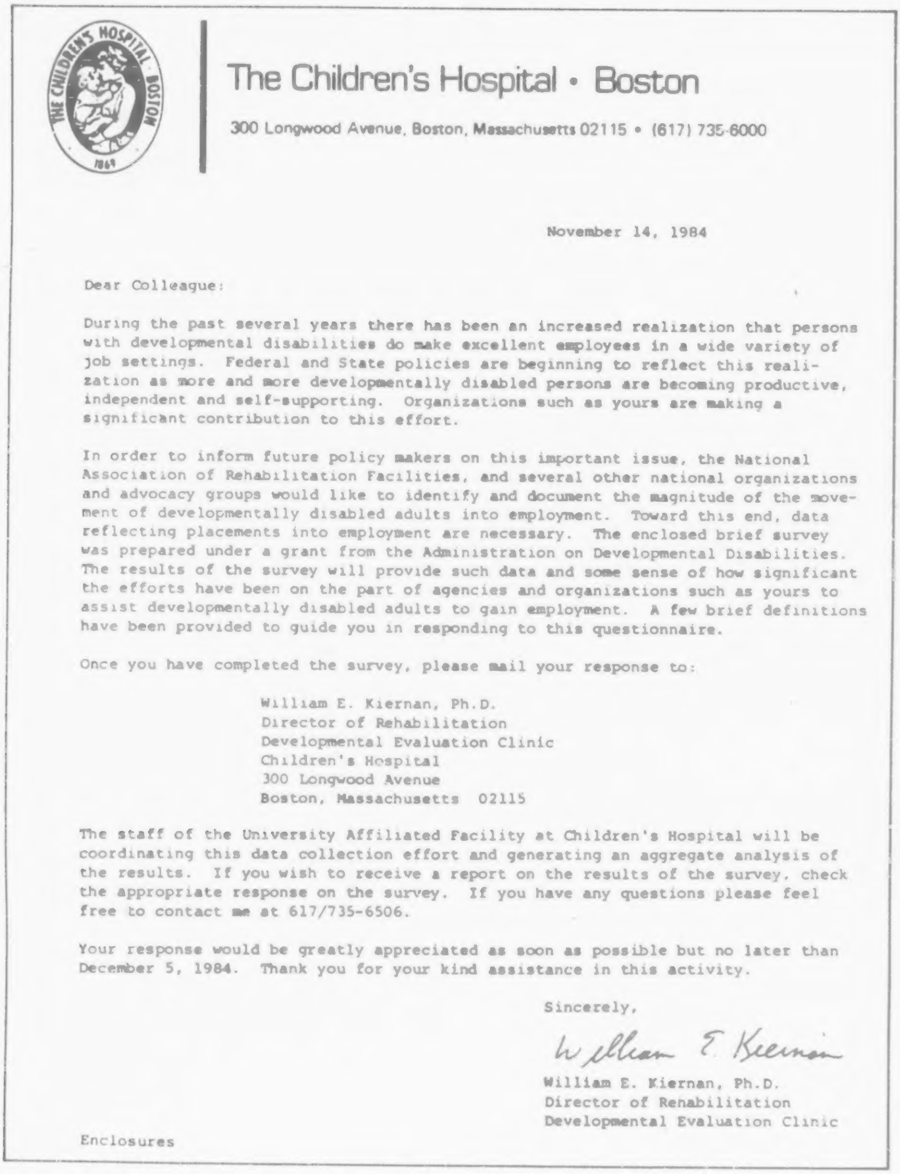
TABLE 17

Annual Estimated Return on Investment to Society

A. Tax Contribution	
Federal Income Tax	$ 6,429,204
State Income Tax	3,326,926
State Unemployment Tax	4,630,775
Federal Unemployment Tax	823,249
Social Security (individual contribution)	7,547,229
B. Corporate Contribution	
Social Security	7,547,229
C. Transfer Payments	
Reduction in SSI	33,339,825
Medicaid Reductions	507,532
D. Alternative Program Cost ($16 per day per person average)	71,040,320
Total Estimated Societal Benefit	$135,192,289

APPENDICES

1. Initial Survey Letter
2. Definitions Included in Survey
3. Survey Form



The Children's Hospital • Boston

300 Longwood Avenue, Boston, Massachusetts 02115 • (617) 735-6000

November 14, 1984

Dear Colleague:

During the past several years there has been an increased realization that persons with developmental disabilities do make excellent employees in a wide variety of job settings. Federal and State policies are beginning to reflect this realization as more and more developmentally disabled persons are becoming productive, independent and self-supporting. Organizations such as yours are making a significant contribution to this effort.

In order to inform future policy makers on this important issue, the National Association of Rehabilitation Facilities, and several other national organizations and advocacy groups would like to identify and document the magnitude of the movement of developmentally disabled adults into employment. Toward this end, data reflecting placements into employment are necessary. The enclosed brief survey was prepared under a grant from the Administration on Developmental Disabilities. The results of the survey will provide such data and some sense of how significant the efforts have been on the part of agencies and organizations such as yours to assist developmentally disabled adults to gain employment. A few brief definitions have been provided to guide you in responding to this questionnaire.

Once you have completed the survey, please mail your response to:

William E. Kiernan, Ph.D.
Director of Rehabilitation
Developmental Evaluation Clinic
Children's Hospital
300 Longwood Avenue
Boston, Massachusetts 02115

The staff of the University Affiliated Facility at Children's Hospital will be coordinating this data collection effort and generating an aggregate analysis of the results. If you wish to receive a report on the results of the survey, check the appropriate response on the survey. If you have any questions please feel free to contact me at 617/735-6506.

Your response would be greatly appreciated as soon as possible but no later than December 5, 1984. Thank you for your kind assistance in this activity.

Sincerely,

William E. Kiernan

William E. Kiernan, Ph.D.
Director of Rehabilitation
Developmental Evaluation Clinic

Enclosures

DEFINITIONS

A Developmental Disability

- is a severe, chronic disability of a person which is attributable to a mental or physical impairment or a combination of mental and physical impairments
- is manifest *BEFORE THE AGE OF 22*
- is likely to continue indefinitely
- results in substantial functional limitation in three or more of the following areas of life activity: self care, receptive and expressive language, learning, mobility, self direction, capacity for independent living, or economic self sufficiency
- reflects the need for a combination and sequence of special, interdisciplinary or generic care, treatment or other services which are of lifelong or extended duration and individually planned and coordinated

Competitive Employment

Full or part-time non-subsidized employment (paid at least at the equivalent of minimum wage per hour worked) and includes certain enclaves, work crews, and employment in regular job sites even when follow along services are provided.

a. **Full-Time Employment:**
Employed 35 hours per week or more

b. **Part-Time Employment:**
Employed less than 35 hours per week

Sheltered Employment:

Full or part-time subsidized employment within a controlled environment (typically paid at less than the minimum wage).

SURVEY
Employment of Adults with Developmental Disabilities

Name of Organization:
Address:
City/State/Zip Code:
Telephone Number:

Name of Person Completing Survey:

I would be interested in receiving the summary of this survey ____ yes ____ no

Please answer questions 1-4 as accurately as possible. Your attention to questions 5-7, though optional, would be of great assistance.

1. To how many persons did your organization provide vocational services from October 1, 1983 to September 30, 1984? ________

   Of that number, how many would by definition be considered developmentally disabled? ________

2. Within the same time period (10/1/83 to 9/30/84), how many developmentally disabled persons were placed in:

	Full-time	Part-time
competitive employment	________	________
sheltered employment?	________	________

3. How many of those developmentally disabled persons placed in competitive employment from 10/1/83 to 9/30/84 remained on the job for more than 60 days?

Full-time	Part-time
________	________

4. How many developmentally disabled persons were placed in competitive employment from 10/1/82 to 9/30/83?

Full-time	Part-time
________	________

---

5. Of those developmentally disabled persons placed from 10/1/83 to 9/30/84, what is the:
   a) average (mean) age at the time of placement in:
      competitive employment ____ years
      sheltered employment ____ years
   b) age range (youngest to oldest) at time of placement in:
      competitive employment ______ to ____ years
      sheltered employment ______ to ____ years

6. Of those developmentally disabled persons who were placed in competitive employment from 10/1/83 to 9/30/84, at the time of placement what was:

	Full-time	Part-time
a) the average wage per hour	$ ____ /hr.	$ ____ /hr.
b) the average number of hours worked per week	____ hrs	____ hrs

7. Please list the types of full and part time competitive jobs in which developmentally disabled persons were placed and the number of placements for each.

Title	Number Placed
________	________
________	________
________	________
________	________
________	________
________	________
________	________
________	________
________	________
________	________

Please use this space for any additional comments.

Thank you.

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EMPLOYMENT SURVEY FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

A National Survey
July 1986

Conducted by:

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A project supported in part by a grant from the Department of Health and Human Services, Office of Human Development Services, Administration on Developmental Disabilities (03DD0135).

Foreword

It has been three years since President Reagan proclaimed 1983-1992 as The National Decade of Disabled Persons, launching the Presidential Initiative to expand private sector job opportunities for persons with developmental disabilities. The Administration on Developmental Disabilities within the Office of Human Development Services is one of several federal agencies which have implemented a strategy to translate this vision into action.

We have made significant progress toward systematic change in the developmental disabilities' employment and training programs. Specifically, we have guided the system toward productivity, independence, and community integration, and away from the previous emphasis on long-term dependency. A key to this effort has been our ability (as government agencies, service providers, and individuals) to work together. The private sector's interest has been essential, but equally essential has been our willingness, as professionals, to adapt programs so that our clientele can be prepared for employment in the most productive and integrated settings possible.

Our strategies have been to stimulate private sector demand for workers with disabilities and to encourage support agencies and training facilities to meet that demand. We obtained the cooperation of major trade associations, consumer organizations and rehabilitation facilities and developed a marketing campaign for the private sector.

In 1984, more than 25,000 persons with developmental disabilities were estimated to have obtained competitive employment. As revealed in this report, the 1985 total exceeds our goal of placing 50,000 persons with developmental disabilities into employment in real-work settings. Many states have become quite involved in employment activities, sponsoring symposia which link employers and service providers and which heighten awareness that persons with developmental disabilities are capable workers. Under the Developmental Disabilities Act of 1984 (P.L. 98-527), every state will be required to include employment-related activities as a service priority in the state plan, thus underlining the systematic change toward which we have been working.

This National Employment Survey documents the movement of adults with developmental disabilities into a wide variety of jobs in integrated work settings. The economic benefits to society and to the individuals are substantial. It is my firm belief that adults with developmental disabilities will continue to make a positive contribution to society, as employment opportunities expand. The accomplishments of the employment initiative and the many other federal, state and local efforts to increase employment opportunities are the beginning of an evolution demonstrating that the contributions of adults with developmental disabilities to society, to the economy, and to themselves can and will be substantial.

Dr. Jean K. Elder, Ph.D.
Acting Assistant Secretary
Office of Human Development Services
Department of Health and Human Services

Acknowledgments

As in any national research effort, a great amount of energy, support and dedication must be present, not only among those charged with the actual research, but also among those who will be asked to help: the respondents, the secretarial staff, professional colleagues and many more. It has been the good fortune of the researchers of this survey to have ongoing support from such persons as the Acting Assistant Secretary, Office of Human Development Services, Dr. Jean K. Elder, Ph.D.; the director of the Employment Initiative, Mr. Raymond Sanchez; and, most notably, the regional office staff of the Administration on Developmental Disabilities (ADD). The completion of this effort would not have been possible without their support. Our own staffs in Boston and Nebraska likewise have been invaluable resources in this massive effort, from stuffing envelopes to entering data into the computer. Research is easy with a little help from our friends and the end result is much more significant in light of their efforts.

It has been a job, we feel, that has produced vital national data regarding the employment of adults with developmental disabilities.

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Introduction

Employment has long been viewed as both a means of economic self-sufficiency and of personal and professional identity (Wright, 1980). The concept of work and the status of work within society have been central to the establishment of a sense of belonging and participation for most adults. Society values employment and assigns status to various occupations. This status, combined with the economic gains realized through employment, often serves to define the social, interpersonal and residential environments within which the individual relates (Warr, 1984).

From an economic perspective, measures such as unemployment rates and levels of productivity are used to reflect the health of the society in general (Poindexter, 1981). Such measures of economic well-being serve to further reinforce the importance of work as a desirable and acceptable activity. Although work is viewed as a desired and central activity for most adults, the U. S. Commission on Civil Rights (1983) reported that the unemployment rate for persons with disabilities was between 50 and 75 percent. Such findings imply that the role and/or perception of the role of the adult with a disability is one of dependence, or of being a non-contributing member of society.

The focus upon employment for adults with severe disabilities, though noted in the Rehabilitation Amendments of 1973, was not fully recognized until the passage of the Comprehensive Rehabilitation Services and Developmental Disabilities Act of 1978 (Kiernan, 1979). Recognition of the importance of employment even for individuals with the most severe disabilities has become more established during the past decade (Schalock, 1983; Wehman, 1981; Horner & Bellamy, 1979). A number of demonstration programs in Oregon, Virginia, Massachusetts, Washington, Vermont, and Illinois were created to provide services to adults with severe disabilities within real work settings (Kiernan & Stark, 1986; Rusch, 1986).

Employment of adults with developmental disabilities (see appendix for definition of developmental disabilities) received national attention through the efforts of the Presidential proclamation of the "National Decade of Disabled Persons." The White House initiative on employment has focused considerable effort on increasing awareness of the private sector's capacity to provide expanded employment opportunities for persons with developmental disabilities. This initiative, under the leadership of Dr. Jean K. Elder, Acting Assistant Secretary of the Office of Human Development Services, reflects a major marketing and development effort to enhance employment opportunities for adults with developmental disabilities. In conjunction with this effort, the Office of Special Education and Rehabilitation Services (OSERS) initiated development of supported employment programs. Moreover, OSERS' recent funding of first 10 and later an additional 17 statewide initiatives in supported employment, the ongoing support of the Rehabilitation Services Administration (RSA), and RSA's attempt to increase employment opportunities for adults with severe disabilities have all added to the federal emphasis on employment. These administrative efforts, along with the legislative changes in the Developmental Disabilities Act (P.L. 98-527), have given employment a higher priority within the areas of public policy, service delivery, and economic development.

The movement from sheltered employment into real work settings has been established nationally through numerous demonstration programs (Bellamy, Horner, & Inman, 1979; Schalock, 1983; Bailis, Jones, Schreiber, & Bernstein, 1984; Riccio & Price, 1984). Furthermore, the use of time-limited transitional employment programs, such as the Supported Work Program of the Bay State Skills Corporation (BSSC) in Massachusetts, and the continual expansion of supported employment opportunities have shown that both training and support play important roles in facilitating entry into employment for adults with developmental disabilities (Kiernan & Stark, 1986; Bailis et al., 1984). Many states have modified their approach to the employment needs of these adults by developing various types of supported, transitional, and competitive employment options (Rusch, 1986). Consequently, the focus of many state efforts has shifted from the use of sheltered workshops as the first choice to the use of integrated work settings as a viable alternative.

Earlier efforts in providing training and employment services now are being viewed by many as limiting the opportunities for adults with developmental disabilities (Wehman, Hill, Hill, Brooke, Pendleton, & Britt, 1985). A report published in 1981 by the U.S. Department of Health and Human Services noted that the average earnings of an individual in sheltered employment were about 35 percent of the minimum wage at that time. Earnings during that period for workers with mental retardation, the largest disability group served, were only $417 per year per worker. Other reports (Karan, 1978; Rusch & Mithaug, 1980) have indicated that individual productivity and movement into competitive employment for the worker with a disability are not sufficiently enhanced in a sheltered employment setting. Advocates of supported and transitional employment designs suggest that the natural work setting is a more desirable work training environment, even for workers with severe disabilities (Horner & Bellamy, 1979; Bailis et al., 1984; Riccio & Price, 1984).

The present study was designed to document changes in the placement patterns of adults with developmental disabilities as the utilization of real work settings increases. Data were collected on three types of employment: transitional training, supported and competitive employment. The study documents benefits which are realized by the individual and society as a result of creating employment opportunities in integrated work settings. A previous research effort examining employment opportunities for adults with developmental disabilities verified that during a 12-month period (Oct. 1, 1983 to Sept. 30, 1984) more than 7,075 adults with developmental disabilities were placed into competitive employment (Kiernan & Ciborowski, 1985). This study collected national data on employment outcomes for adults with developmental disabilities. The reported findings identified benefits realized by the individual and society as a result of employment. The present study aims to further refine the data on employment by focusing on a larger sample, as well as by more systematically defining the types of employment accessed: transitional training, supported, or competitive.

The following four statements or beliefs reflect the broad assumptions which guided the researchers in developing the methodology, data collection, and analysis procedures. As such, they serve as the hypotheses of the study.

1. There is an increase in the placement activities of adults with developmental disabilities.
2. The increase reflects the utilization of transitional training, supported, and competitive employment opportunities.
3. The economic benefits realized through these types of employment are greater than those from sheltered employment, for both the individual and society; and
4. The placements being made reflect a variety of occupational categories.

Method

Sample Selection

The targeted sample for the National Survey of Employment of Adults with Developmental Disabilities included vocational rehabilitation agencies, organizations and/or facilities which met one or both of the following criteria during the survey period: 1) placed adults with developmental disabilities into transitional, supported, or competitive employment settings, and 2) provided sheltered employment for adults with developmental disabilities (see Definitions section). A comprehensive list of such organizations was compiled, beginning with 1,629 organizations, agencies and/or facilities surveyed by the Developmental Evaluation Clinic (DEC) the preceding year (Kiernan & Ciborowski, 1985). All Project With Industry programs were added to this list. Following contact by regional offices of the Administration on Developmental Disabilities with state Mental Retardation and Developmental Disabilities offices and Developmental Disabilities Councils, additional organizations were identified and included in the survey sample. A total sample of 3,652 agencies, organizations, and/or facilities was obtained. The investigators realized some would not meet the criteria for inclusion in the study. Hence, a secondary goal of the survey was to establish an accurate list of those organizations providing employment services to adults with developmental disabilities.

Survey Instruments

In developing any survey instrument, the conflict between the amount of data desired by the investigators and the amount which can be expected from respondents necessitates careful review of the research design. With a goal of establishing a national data base on the employment of adults with developmental disabilities, the investigators chose to cluster the sample by state and then to randomly subdivide it within each state cluster. As much detailed data as possible were requested of one group, while a more general collection procedure was undertaken with the remaining group. Based on the assumption that higher response rates would result from less time-consuming surveys, these procedures were employed to enhance total response rates while maximizing the quality of the data received.

General survey. Maintaining the state by state groupings, two-thirds of the sample list were randomly selected to receive the General Survey (2,435 addresses). However, after adjustments for address duplications, branch offices, and letters returned without forwarding addresses, 2,100 remained in the sample. The General Survey asked respondents to report aggregate data on the number of persons placed, average age, age range, wages, hours worked per week, and weeks worked in the following employment settings: sheltered, transitional training, supported, and competitive employment. Types of occupations were requested for competitive placements. Furthermore, comparison data were solicited for the number of persons placed during the 12 months prior to the survey period (Oct. 1, 1983 to Sept. 30, 1984).

Definitions. The following functional definition of developmental disabilities was included in the survey packet as a guide for respondents: 1) a chronic disability attributable to a mental or physical impairment or both; 2) is manifest before the the age of 22; 3) is likely to continue indefinitely; 4) results in substantial limitation in three or more areas of life activity, including self care, receptive and expressive language, learning, mobility, self direction, capacity for independent living, or economic self sufficiency; and 5) reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of life-long or extended duration. In addition, the following definitions of employment options were mailed with the survey:

1. **Sheltered employment.** Employment in a controlled environment, where payment is typically at less than the minimum wage.
2. **Transitional training/employment.** Employment which provides time-limited support leading to competitive employment, where payment is typically at less than the minimum wage.
3. **Supported employment.** Employment which requires intensive ongoing support, utilizing worksites where persons without disabilities are employed, where payment is most often at less than the minimum wage;
4. **Competitive employment.** Unsubsidized employment where payment is at or above the minimum wage (including certain enclaves, work crews, and employment in regular jobs, even when follow-along services are provided.)

Detailed survey. The remaining agencies, organizations, and/or facilities on the master list (1,217) received a survey soliciting individual client data. This sample was likewise adjusted for address duplications, branch offices, and lack of forwarding addresses, yielding a total of 1,037. The Detailed Survey requested age, gender, IQ, hourly wages, hours worked per week, weeks worked, setting prior to placement, type of placement, and current employment environment for each person placed in transitional training, supported, and competitive employment. Information was requested on the nature of supports, Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI), and on whether employment impacted these support structures. Data regarding knowledge of the work incentives (Section 1619 (a) and (b)) of the Social Security regulations and their use were also collected (see Appendix for definitions of 1619 (a) and (b)). Lastly, for sheltered employment placements and for placements made during the previous twelve months, only aggregate data were requested.

Survey Procedure

Both survey instruments were mailed to the respective samples in late November 1985. Two weeks later, reminder post cards were sent to all nonrespondents. Four weeks after the initial mailing, nonrespondents received another copy of the questionnaire. Moreover, telephone follow-up of nonrespondents was initiated approximately five weeks after the first mailing. Telephone contacts were completed with 864 (51.9 percent) of the combined nonrespondents for both surveys. Of the General Survey nonrespondents, 113 reported they did not meet the sample criteria of providing employment services to adults with developmental disabilities, while 31 of the Detailed Survey nonrespondents fell within this category.

Each questionnaire was edited upon receipt. Facilities which provided inconsistent or unclear information were contacted by telephone for clarification. Validation procedures for data entry were conducted with a recorded error rate of less than 1 percent.

Results

The data obtained from both the General and Detailed surveys were analyzed to provide information regarding six major areas of interest related to the project's stated hypotheses. These areas include: (1) the current placement activities among agencies providing vocational services to adults with developmental disabilities; (2) earnings data for those persons in sheltered, transitional training, supported or competitive employment environments; (3) the occupational categories into which adults with developmental disabilities are placed; (4) the type of movement pattern exhibited from one employment status to another; (5) client characteristics among the various placement options; and (6) knowledge of section 1619 (a) and (b) of the Social Security regulations and the impact of employment on a person's Social Security benefits. Each of these topics is addressed in subsequent sections, along with the particular data source.

Characteristics of Responding Facilities

The General Survey yielded a 49.9 percent response rate, with 1048 organizations responding. Of these respondents, 242 reported reported they either did not provide employment services or did not serve adults with developmental disabilities. In the Detailed Survey, 424 facilities responded, a 40.9% rate of return; 111 of these respondents stated they did not meet the survey eligibility guidelines.

Consequently, a total of 1,119 facilities provided data for the surveys (806 for the General Survey and 313 for the Detailed Survey). These 1,119 facilities were providing vocational services to 112,996 adults with developmental disabilities, who represented 70.5 percent of the total clientele served by the facilities. The number of persons served as reported from each survey is presented in Table 1.

Table 1

Number of Persons Served in Reporting Facilities Providing Vocational Services (Oct. 1, 1984–Sept. 30, 1985)

Population	General Survey	Detailed Survey	Combined
Total Number	120,724	39,645	160,369
Adults with Developmental Disabilities	84,379	28,617	112,996
Percent Adults with Developmental Disabilities	69.9%	72.2%	70.5%

Table 2 summarizes the sheltered employment and placement data for the 112,996 adults with developmental disabilities by state and territory. These data represent the

Table 2

Sheltered Employment and Placement Data by State and Territory (General and Detailed Surveys)

State and Number Returned*	Adults With Developmental Disabilities Served	# Reported In Sheltered Served	Total Placed (10/1/84–9/30/85) Into:		
			Transitional Training/ Employment	Supported Employment	Competitive Employment
Alaska (3)	108	70	10	19	11
Alabama (8)	1,860	591	9	0	242
Arkansas (17)	667	377	5	42	208
American Samoa (1)	80	0	36	12	33
Arizona (13)	734	353	129	56	70
California (97)	10,622	8,018	483	316	451
Colorado (11)	1,381	772	65	60	106
Connecticut (26)	3,709	2,849	391	161	365
Delaware (1)	109	0	0	0	0
D.C. (1)	45	45	0	0	0
Florida (33)	2,704	1,532	176	73	271
Georgia (13)	1,573	615	260	49	156
Hawaii (8)	409	153	18	15	60

Table 2 (continued)

State and Number Returned[a]	Adults With Developmental Disabilities Served	# Reported In Sheltered Served	Total Placed (10/1/84–9/30/85) Into: Transitional Training/ Employment	Supported Employment	Competitive Employment
Iowa (37)	2,491	1,606	118	52	101
Idaho (7)	562	317	28	27	59
Illinois (32)	5,349	2,599	267	127	528
Indiana (31)	3,665	2,442	68	53	364
Kansas (17)	2,726	780	17	327	858
Kentucky (13)	1,287	408	89	30	357
Louisiana (10)	736	247	58	21	53
Massachusetts (30)	3,408	1,604	150	430	420
Maryland (20)	2,119	926	124	74	654
Maine (12)	623	391	94	49	71
Michigan (32)	4,301	1,916	318	213	451
Minnesota (62)	3,890	1,824	188	402	217
Missouri (19)	1,821	743	22	15	220
Mississippi (15)	1,256	742	278	31	259
Montana (12)	431	263	8	29	16
N. Carolina (20)	2,525	814	103	58	478
N. Dakota (7)	393	118	11	41	51
Nebraska (24)	1,044	821	86	117	117
New Hampshire (7)	539	166	72	106	113
New Jersey (35)	3,634	2,481	146	29	345
New Mexico (10)	592	467	2	21	50
Nevada (6)	433	382	27	7	24
New York (81)	11,373	9,284	472	361	1,026
Ohio (16)	3,523	1,435	151	45	190
Oklahoma (22)	832	720	122	69	54
Oregon (24)	928	751	46	25	64
Pennsylvania (53)	8,587	4,852	187	107	915
Puerto Rico (4)	123	3	22	0	22
Rhode Island (12)	907	715	27	10	94
S. Carolina (13)	1,555	1,189	233	8	121
S. Dakota (8)	467	275	31	31	72
Tennessee (26)	2,406	1,441	160	99	102
Texas (17)	1,595	553	306	77	350
Utah (6)	275	219	3	5	10
Virginia (20)	2,613	1,322	72	35	303
Virgin Islands (1)	15	15	0	0	0
Vermont (7)	140	81	2	1	70
Washington (44)	1,890	1,075	93	116	234
Wisconsin (40)	3,555	2,490	211	152	389
W. Virginia (12)	586	320	223	0	16
Wyoming (2)	110	45	0	0	41
Surveys Not Identified by State (21)	1,536	876	56	31	154
Totals (1,119)	112,996	65,093	6,273	4,234	12,006
Percent of Total # of Adults with Developmental Disabilities Served		57.6%	5.6%	3.7%	10.6%

[a] The number returned includes only those surveys which met the survey criteria of providing vocational services to adults with developmental disabilities. See Table 18 for total response rate, including facilities which did not meet the criteria.

combined totals as reported on the General and Detailed surveys. Nearly 58 percent of the adults with developmental disabilities were reported as being placed or served in sheltered employment. During the period from Oct. 1, 1984 to Sept. 30, 1985, 5.6 percent of the facilities' clientele with developmental disabilities were placed into transitional training/employment; 3.7 percent into supported employment; and 10.6 percent into competitive employment. These placements include a total of 22,513 persons. Thus, the combined placements into employment in these real work settings represent a 19.9 percent placement rate.

Facilities were grouped by size (number of clients) into nine categories to analyze the potential effect of facility size on patterns of placement rates. These data are presented in tables 3 and 4. The top portion of Table 3 presents the total number of persons who received vocational services, as well as that portion reported to be developmentally disabled, by facility size category. As revealed

Table 3
Sheltered Employment and Placement Data by Size of Organization (General and Detailed Surveys Combined)

Facility Size (# of Clients)	Total Persons Served	Adults With Developmental Disabilities Served	% of Adults With Developmental Disabilities Served
1-25	2,574	2,445	95.0%
26-50	9,068	8,197	90.4%
51-75	8,723	7,632	87.5%
76-100	9,300	7,916	85.1%
101-125	9,840	7,955	80.8%
126-150	9,551	7,733	81.0%
151-175	9,125	6,955	76.2%
176-200	9,500	6,888	72.5%
200 +	92,688	57,245	61.8%
Totals	160,369[a]	112,966	70.5%

		Number Organizations Providing:			
Facility Size (# of Clients)	Total # Organizations	Sheltered Employment	Transitional Training/Employment	Supported Employment	Competitive Employment
1-25	160 (14)[b]	100 (12)	46 (11)	45 (12)	72 (9)
26-50	236 (21)	177 (21)	82 (19)	93 (26)	141 (18)
51-75	137 (12)	110 (13)	43 (10)	45 (12)	90 (11)
76-100	104 (9)	85 (10)	39 (9)	34 (9)	76 (10)
101-125	87 (8)	67 (8)	40 (10)	25 (7)	72 (9)
126-150	68 (6)	52 (6)	24 (6)	21 (6)	52 (7)
151-175	56 (5)	46 (5)	26 (6)	17 (5)	49 (6)
176-200	50 (5)	42 (5)	24 (6)	16 (4)	45 (5)
200 +	217 (20)	173 (20)	99 (23)	67 (19)	195 (25)
Totals	1,115[a]	852	423	363	792

[a] These totals vary slightly from those reported in Table 2 due to missing facility size data on 0.4 percent of the returned surveys.
[b] Percent within column total.

in this table, the larger the facility, the smaller the percentage of persons with developmental disabilities. The lower section of Table 3 summarizes the number of organizations, by size, providing sheltered, transitional training, supported or competitive employment placement services. The most common service provided was sheltered employment, followed in order by competitive, transitional and supported employment.

The top section of Table 4 summarizes, again by facility size, the number of adults with developmental disabilities who either were in sheltered employment or were placed in one of the other employment settings during the survey period (Oct. 1, 1984 to Sept. 30, 1985). For those placements other than sheltered, 53 percent were into competitive employment, followed by 28 percent into transitional training, and 19 percent into supported. A placement rate was computed in order to evaluate the placement activities of different size facilities; this appears in the lower section of Table 4. The most consistent trends are revealed for supported and competitive employment settings. Specifically, small facilities placed a larger percentage of their clientele into supported employment than large facilities, while large facilities had a higher competitive employment placement rate (except for the smallest facility size category of 1-25). Transitional training placements were almost evenly distributed across the size categories. Finally, the smallest facility size category (1-25) achieved the highest placement rate for competitive and supported employment settings, in addition to the second highest placement rate for transitional employment.

Table 4
Placement Data by Size of Organization (General and Detailed Surveys Combined)

Facility Size (# of Clients)	# Reported in Sheltered Employment	Total Placed (10/1/84–9/30/85) Into: Transitional Training/Employment	Supported Employment	Competitive Employment
1-25	1,518 (2)[a]	261 (4)	225 (5)	405 (3)
26-50	5,458 (8)	523 (8)	597 (14)	651 (5)
51-75	5,398 (8)	442 (7)	543 (13)	665 (6)
76-100	5,312 (8)	392 (6)	374 (9)	670 (6)
101-125	5,118 (8)	647 (10)	292 (7)	756 (6)
126-150	4,674 (7)	418 (7)	285 (7)	799 (7)
151-175	4,593 (7)	866 (14)	322 (7)	926 (8)
176-200	4,472 (7)	437 (7)	153 (4)	693 (6)
200 +	28,477 (44)	2,283 (37)	1,443 (34)	6421 (53)
Totals	65,020[b]	6,269	4,234	12,006

Facility Size (# of Clients)	Placement Rate[c] For: Transitional Training/Employment	Supported Employment	Competitive Employment
1-25	10.7%	9.2%	16.6%
26-50	6.4%	7.3%	7.9%
51-75	5.8%	7.1%	8.7%
76-100	5.0%	4.7%	8.5%
101-125	8.1%	3.7%	9.5%
126-150	5.4%	3.7%	10.3%
151-175	12.5%	4.6%	13.3%
176-200	6.3%	2.2%	10.1%
200 +	4.0%	2.5%	11.2%
Overall Rates:	5.6%	3.7%	10.6%

[a] Percent within column total

[b] Missing data by size account for inconsistencies with totals reported in Table 2

[c] The placement rate was computed as follows:
Number of persons placed in the employment setting divided by total number of adults with developmental disabilities served in the size category equals percent of adults with developmental disabilities placed

Sheltered Employment Data

Questions were asked on both surveys regarding the employment status (full or part-time), wages, and hours worked per week of persons within the facility's sheltered work environment. These data are summarized in Table 5 for the two surveys. Several general conclusions are evident.

Table 5
Sheltered Employment Data (Oct. 1, 1984–Sept. 30, 1985)

Variable	General Survey	Detailed Survey	Combined
1. Employment Status			
Full Time	16,763	4,184	20,947
Part Time	29,360	14,786	44,146
3. Hours Per Week (Weighted Means)			
Full Time	30.6 (± .05)[a]	30.2 (± .15)	30.5
Part Time	23.7 (± .05)	22.6 (± .07)	23.3
2. Wages Per Hour (Weighted Means)			
Full Time	$1.51 (± .008)	$1.30 (± .014)	$1.47
Part Time	$1.25 (± .004)	$1.21 (± .006)	$1.24

Table 5B
Sheltered Wage Data by Percentile
(General and Detailed Surveys Combined)

Wages	Number Adults with Developmental Disabilities in Each Category	Percent in Each Category
Less than or equal to $0.76	14,314[b]	25%
Less than or equal to $1.09	14,046	50%
Less than or equal to $1.67	14,136	75%
Less than or equal to $3.00	11,398	95%
More than $3.00	2,825	5%
	Total 56,719	

[a] Standard error of the mean

[b] These numbers are smaller than the totals reported in #1 because of missing data on the wage variable.

The employment status indicates that 32 percent were employed full time within the sheltered work environment, and 68 percent were employed part time. Full-time status persons averaged (weighted means) 30.5 hours per week at $1.47 per hour, and part-time status persons averaged 23.3 hours per week at $1.24 per hour. Table 5B reveals that 50 percent of the individuals in sheltered employment earned $1.09 per hour or less, while 75 percent earned $1.67 or less. Less than 5 percent of the population served in sheltered employment earned more than $3.00 per hour.

Employment Data for Persons Placed

Table 6 summarizes General Survey data for persons placed into transitional training, supported or competitive employment from Oct. 1, 1984 through Sept. 30, 1985. A number of significant trends are apparent in these data. First, part-time status is more common in transitional training and supported employment than it is in competitive employment. Second, the average age at placement differs across employment environments, with the youngest average age associated with competitive employment.

Table 6
Employment Data for Adults with Developmental Disabilities Placed Into Transitional, Supported or Competitive Employment
(General Survey: Oct. 1, 1984–Sept. 30, 1985)

	Employment Environments		
Variable	Transitional Training/Employment	Supported Employment	Competitive Employment
1. Number Placed:			
Full Time	2,797	1,440	7,521
Part Time	3,201	2,464	2,627
2. Average Age at Placement (Weighted Means)	29.0 (± .09)[a]	30.8 (± .10)	28.6 (± .05)
3. Wages Per Hour (Weighted Means)			
Full Time	$2.67 (± .02)	$3.16 (± .05)	$3.96 (± .01)
Part Time	$2.11 (± .02)	$2.26 (± .02)	$3.56 (± .01)
4. Hours Per Week (Weighted Means)			
Full Time	35.8 (± .07)	35.7 (± .13)	38.3 (± .03)
Part Time	19.9 (± .17)	19.2 (± .20)	20.8 (± .14)
5. Yearly Placement Comparisons			
Full Time			
1983–84	1,737	1,020	4,993
1984–85	2,797	1,440	7,521
Part Time			
1983–84	1,462	1,222	1,448
1984–85	3,201	2,464	2,627

[a] Standard error of the mean

Thus, there is a statistically significant difference (.05 level) in the age of persons in competitive employment compared with those in supported employment. Third, average wages increase from transitional, to supported, to competitive employment. Finally, the data in the lower portion of Table 6 indicate an increase in placements across the three employment environments from 1983-84 to 1984-85. The specific increases were 87 percent for transitional, 74 percent for supported, and 58 percent for competitive employment.

Placement data were also available from the Detailed Survey for 1,935 individuals. A general description of these persons is presented in Table 7. For females and males combined, 3.3 percent were reported as being in the severe/profound category of retardation, 15.5 percent in the moderate category, 40.9 percent in the mild category; while 40.3 percent were reported to have IQ's of 70 or above. This distribution by IQ score is consistent with the Administration on Developmental Disabilities' expected diagnostic distribution based on the new definition of developmental disabilities: 35 percent mental retardation, 10 percent serious emotional disturbance, 17 percent sensory impaired, and 38 percent physically impaired. It was noted that many individuals would likely be represented in more than one category and that the severity of disabilities might vary substantially within and across categories (Administration on Developmental Disabilities, 1981).

The employment data by disability level are presented in Table 8. A consistent trend is evident in these data: starting wages, average hours worked per week, and weeks worked since placement all increased for those with higher levels of cognitive ability (using IQ as the criterion for disability).

Table 7
Age and Gender of Developmentally Disabled Adults Included in the Detailed Survey by Disability Level[a]

	Males		Females	
Disability Level[a]	Average Age	Number	Average Age	Number
Severe/Profound	31.1 (± 1.69)[b]	36	35.4 (± 2.35)	27
Moderate	30.9 (± .66)	186	31.2 (± .94)	114
Mild	29.2 (± .42)	462	30.1 (± .55)	330
70 or Above	28.2 (± .41)	478	29.5 (± .58)	302
Overall Average	29.1	1162	30.2	773

[a] Disability level was defined on the basis of a standardized IQ measure as follows: Profound (24 and below); Severe (25-39); Moderate (40-54); Mild (55-69); and 70 or above. Severe and profound groups were combined due to small sample size.

[b] Standard error of the mean

Table 8
Employment Data by Disability Level
(Detailed Survey)

Disability Level	Number of Placements by Level[a]	Starting Wage	Average Hours per Week	Weeks Worked since Placement
Severe/Profound	61	$3.00[b] .20[c] $0.54-$6.97[d]	17.6 1.5 1-40	19.1 1.92 2-57
Moderate	330	$3.32 .06 $0.25-$9.50	23.9 .63 1-40	21.9 .96 1-61
Mild	848	$3.38 .03 $0.25-$9.50	28.1 .38 1-40	22.2 .62 1-78
Above 70	852	$3.85 .04 $0.45-$12.59	32.6 .34 1-48	22.1 .61 0.5-74

[a] The variance from the number reported in Table 7 is a result of: 1) missing data on 1.2 percent of the placement-movement pattern, and 2) Table 8 data is based on total *placements*, while Table 7 reflects total individuals placed (8.3 percent were placed more than once).

[b] Mean

[c] Standard error of the mean

[d] Range

Some respondents reported number of weeks worked up to the time the survey was answered, which accounts for the values above 52 weeks.

Placements by Occupational Categories

The types of jobs into which persons were placed from Oct.1, 1984 to Sept. 30, 1985 were coded according to one-, two- and three-digit occupational categories from the Dictionary of Occupational Titles (D.O.T.) (U.S. Department of Labor, 1977). The D.O.T. codes provide three levels of specificity. The one-digit codes group job titles into very general occupational categories, while the two- and three-digit codes are increasingly more specific regarding the work performed.

These data are reported separately in the following four tables for the General and Detailed surveys. Table 9 summarizes placements for the two surveys by the more general one-digit occupational categories. Across the two surveys, 68 percent of the placements were included in the occupational categories of clerical-sales, service and benchwork.

A more specific listing of the job tities included in these categories is found in Table 10, which summarizes placements utilizing the more detailed two-digit occupational coding system. In addition, Table 10 lists the absolute frequency and the relative frequency percent for those job categories comprising one or more percent of the placements. Two job categories represented the largest placement category: food and beverage preparation/service and building (janitorial) services.

Table 9

Placement by Occupational Categories[a]
(Oct. 1, 1984–Sept. 30, 1985)

Category Label	General Survey			Detailed Survey		
	Absolute Frequency	Relative Frequency Percent	Cumulative Frequency	Absolute Frequency	Relative Frequency Percent	Cumulative Frequency
1. Professional, Technical, Managerial	98	1.0	1.0	29	1.2	1.2
2. Clerical, Sales	993	10.1	11.1	265	10.6	12.1
3. Service	4,574	46.7	57.8	1,338	53.7	67.3
4. Agriculture, Forestry, Fishing	328	3.3	61.1	111	4.5	71.8
5. Processing	35	0.4	61.5	26	1.0	72.9
6. Machine Trades	192	2.0	63.4	38	1.5	74.5
7. Benchwork	890	9.1	72.4	248	10.0	84.7
8. Structural Work	254	2.6	75.1	88	3.5	88.3
9. Miscellaneous	399	4.1	79.2	163	6.5	95.1
10. Other	548	5.6	84.8	117	4.7	99.9
– Job Category Not Listed	1,492	15.2	100.0	68	0.1	100.0
Total	9,803	100.0		2,491	100.0	

[a] Occupational categories as listed in the *Dictionary of Occupational Titles* (U.S. Department of Labor, 1977).

Table 10

Placements by Two-Digit Occupational Categories[a]
(General & Detailed Surveys Combined)

Category Label	Absolute Frequency	Relative Frequency Percent[b]
Food & Beverage Prep. & Service	2,792	22.7
Building Service	2,088	17.0
Fabrication & Assembly	965	7.8
Lodging & Related Service	616	5.0
Misc. Clerical	444	3.6
Packaging & Handling	426	3.5
Plant Farming	308	2.5
Production & Stock Clerk	242	2.0
Stenography, Typing, Filing	236	1.9
Misc. Personal Service	199	1.6
Construction	169	1.4
Apparel Service	127	1.0
Transportation	114	1.0
Other	665	5.4

[a] As presented in the *Dictionary of Occupational Titles* (U.S. Department of Labor, 1977).
[b] Only those job categories comprising one or more percent were included.

The one-digit code placement data obtained from the Detailed Survey were also analyzed according to occupational category and disability level. The five most prevalent occupational categories are listed in Table 11. For persons with severe/profound retardation, the primary placement categories included service and benchwork. For those in the moderate range of retardation, the primary placements included service, agriculture and benchwork. Placements for individuals diagnosed with mild retardation and for those with IQs above 70 were heavily concentrated in the service areas; however, these individuals were well represented throughout the occupational categories.

Table 11
Placements by Occupational Category and Disability Level (Detailed Survey)

	Disability Level			
Occupational Category	Severe/Profound	Moderate	Mild	70 or Above
Clerical, Sales	6[a] 2.5[b]	15[a] 6.2[b]	80[a] 33.2[b]	140[a] 58.1[b]
Service	47 3.8	240 19.4	524 42.3	427 34.5
Agriculture, Forestry, Fishery	3 2.8	23 21.7	46 43.4	34 32.1
Benchwork	18 7.5	32 13.3	96 39.8	95 39.4
Miscellaneous	0	19 12.2	63 40.4	74 47.4

[a] Number of persons within occupational category
[b] Percent within occupational category

Table 12
Placements by Three-Digit Occupational Categories[a] (General and Detailed Surveys)

Occupation	Absolute Frequency	Relative Frequency Percent
Food and Beverage Preparation & Service		
Host/Hostess or Steward	10	.1
Waiter	19	.2
Bartender	3	.04
Hotel, Restaurant Chef or Cook	57	.8
Misc. Cook	7	.1
Meat Cutter	3	.04
Kitchen Worker	769	11.2
Misc. Food & Beverage Preparation	1,926	28.0
Lodging and Related Services		
Housekeeper, Hotels	199	2.9
Housecleaner, Hotels	280	4.1
Misc. Lodging Occupations	116	1.7
Building and Related Services		
Porter, Cleaner	215	3.1
Janitors	1,843	26.8
Elevator Operator	1	.01
Misc. Building & Related Occupations	23	.3
Fabrication and Repair of Products		
Of Sporting Goods	9	.1
Of Jewelry	9	.1
Of Assorted Products	947	13.8
Packaging and Materials Handling		
Packaging	116	1.6
Moving and Storing Materials	221	3.2
Misc. Packing and Materials Handling	88	1.3

[a] Categories listed were those containing the highest number of placements.

The data presented in Table 12, using the more specific three-digit D.O.T. coding system, reveal a more detailed listing of job titles included in the top five categories reported. Food and beverage preparation, janitorial service, assembly, and lodging services represent occupations with the largest numbers of persons placed for both surveys.

Movement Patterns within Employment Statuses

The Detailed Survey asked respondents to provide individually referenced data according to the person's "setting prior to placement," the "employment environment placed into," and the person's "current employment environment." The prior setting and current employment environment included five employment statuses: transitional training, supported, competitive, sheltered, and unemployed. These data provide the basis for the trends summarized in the following two tables. The general movement patterns across disability levels are shown in Table 13. A general trend is that persons move from sheltered work, unemployed or transitional statuses to either supported or competitive employment.

Table 14 summarizes placement/movement patterns by disability level (according to reported IQ scores).

Table 13
Movement Patterns within Employment Statuses (Detailed Survey)

	Setting Prior To Placement		Employment/Job Environment Placed Into		Current Employment/ Job Environment	
Employment Status	Frequency	Adjusted Frequency (Percent)	Frequency	Adjusted Frequency (Percent)	Frequency	Adjusted Frequency (Percent)
Transitional	448	18.3	275	11.2	147	6.3
Supported	52	2.1	330	13.4	261	11.2
Competitive	102	4.2	1,858	75.4	1,353	58.1
Sheltered	1,096	44.8			238	10.2
Unemployed	750	30.6			329	14.1
Total	2,448		2,463		2,328	

Table 14
Placement/Movement Patterns by Disability Level (Detailed Survey)

Disability Level	Employment Status	Setting Prior to Placement	Employment Environment Placed Into	Current Employment Environment
Severe or Profound	Transitional	9 (11.7)[a]	22 (28.6)[a]	11 (16.4)[a]
	Supported	6 (7.8)	28 (36.4)	20 (29.9)
	Competitive	0	27 (35.1)	24 (35.8)
	Sheltered	31 (40.3)		4 (6.0)
	Unemployed	31 (40.3)		8 (11.9)
Moderate	Transitional	92 (25.9)	47 (13.2)	31 (9.3)
	Supported	6 (1.7)	101 (28.5)	59 (17.6)
	Competitive	7 (2.0)	207 (58.3)	146 (43.6)
	Sheltered	183 (51.5)		47 (14.0)
	Unemployed	67 (18.9)		52 (15.5)
Mild	Transitional	181 (19.0)	132 (13.8)	75 (8.3)
	Supported	20 (2.1)	149 (15.6)	127 (14.1)
	Competitive	39 (4.1)	677 (70.7)	494 (54.8)
	Sheltered	482 (50.6)		103 (11.4)
	Unemployed	231 (24.2)		102 (11.3)
Above 70 IQ	Transitional	153 (16.5)	72 (7.7)	29 (3.3)
	Supported	20 (2.2)	50 (5.4)	53 (6.0)
	Competitive	48 (5.2)	810 (86.9)	593 (66.6)
	Sheltered	348 (37.5)		70 (7.9)
	Unemployed	358 (38.6)		145 (16.3)

[a] Percent within disability category

Those with severe/profound mental retardation were placed about equally into transitional, supported and competitive employment. Significantly, very few returned to sheltered work (Table 14, right column). Individuals with moderate retardation were placed primarily into supported and competitive employment environments. The current employment environments for this group show that the largest percentage remained in competitive employment (43.6 percent). The remaining individuals were more evenly distributed among sheltered and supported employment and unemployment, with fewer placed into transitional training/employment. Persons with mild retardation were placed primarily into competitive employment from sheltered or unemployed categories. If the competitive status changed, there tended to be a return to supported, sheltered or unemployed status, as was seen in the case of individuals in the moderate range. Finally, the general trend for persons with IQ's above 70 was placement into competitive employment. However, if these individuals left their jobs, they tended to become unemployed rather than entering sheltered, supported or transitional employment options. Across all IQ ranges, a separate analysis shows that of the 505 persons who lost their competitive employment status following placement, 7 percent entered transitional training, 8 percent entered supported employment, 32.9 percent entered sheltered employment and 52.1 percent became unemployed.

Employment Retention

Measures of retention in competitive employment were calculated from the data provided in both surveys. In the General Survey, respondents were asked to report on persons who maintained their competitive employment status for more than 60 days. Those placed in part-time competitive employment had a retention rate of 79.2 percent, with those in full-time positions retained at a rate of 76.8 percent. The combined retention rate for the 60-day period was 77.4 percent.

Retention for the Detailed Survey was calculated from the data provided in Table 14. Again, utilizing competitive employment only, retention was calculated for each of the disability levels as follows: 88.8 percent for the severe/profound category, 70.5 percent for the moderate, 73.0 percent for the mild, and 73.2 percent for those with IQs above 70. The combined retention rate across all levels of retardation was 73 percent, while the average time period worked was 22 weeks.

State-by-State Comparisons

Table 15 provides state-by-state data on competitive employment placements and retention for both the General and Detailed surveys. This information enables comparison of individual state performance in the placement of adults with developmental disabilities into competitive employment only. The data reflect retention periods ranging from 60 to 150 days, based on retention measures from both surveys. Lastly, in order to measure the increase in placement activities, data are provided for the prior 12-month period. These data should be interperted with caution since, in some instances, the sample size is small. The intent is to provide information which will illustrate general trends and comparisons for purposes of planning, rather than evaluation.

Table 15
Competitive Employment Placement and Retention Data (General and Detailed Surveys Combined)

State and Number Returned[a]	# of Adults with Developmental Disabilities Served	# Placed Competitive Employment	% Placed	# Retained (60 Days or More)	% Retained[b]	# Placed Previous Year
Alaska (3)	108	11	10	3	27	13
Alabama (8)	1,860	242	13	222	92	184
Arkansas (17)	667	208	31	149	72	186
American Samoa (1)	80	33	41	29	88	–
Arizona (13)	734	70	10	59	84	26
California (97)	10,622	451	4	346	77	351
Colorado (11)	1,381	106	8	93	88	56
Connecticut (26)	3,709	365	10	297	81	269
Delaware (1)	109	0	–	–	–	–
D.C. (1)	45	0	–	–	–	37
Florida (33)	2,704	271	10	196	72	170
Georgia (13)	1,573	156	10	103	66	79
Hawaii (8)	409	60	15	52	87	29
Iowa (37)	2,491	101	4	77	76	94
Idaho (7)	562	59	11	40	68	47
Illinois (32)	5,349	528	10	372	70	407
Indiana (31)	3,665	364	10	274	75	187
Kansas (17)	2,726	858	32	661	77	832
Kentucky (13)	1,287	357	28	244	68	228
Louisiana (10)	736	53	7	38	72	44
Massachusetts (30)	3,408	420	12	333	79	314
Maryland (20)	2,119	654	31	487	75	644
Maine (12)	623	71	11	59	83	59
Michigan (32)	4,301	451	11	153	34	75

Table 15 (continued)

State and Number Returned[a]	# of Adults with Developmental Disabilities Served	# Placed Competitive Employment	% Placed	# Retained (60 Days or More)	% Retained[b]	# Placed Previous Year
Minnesota (62)	3,890	217	6	148	68	119
Missouri (19)	1,821	220	12	153	70	37
Mississippi (15)	1,256	259	21	202	78	228
Montana (12)	431	16	4	15	94	10
N. Carolina (20)	2,525	478	19	338	71	311
N. Dakota (7)	393	51	13	44	86	41
Nebraska (24)	1,044	117	11	114	97	136
New Hampshire (7)	539	113	21	110	97	22
New Jersey (35)	3,634	345	10	265	77	217
New Mexico (10)	592	50	8	37	74	8
Nevada (6)	433	24	6	14	58	19
New York (81)	11,373	1,026	9	728	71	779
Ohio (16)	3,523	190	5	130	68	270
Oklahoma (22)	832	54	7	52	96	43
Oregon (24)	928	64	7	46	72	43
Pennsylvania (53)	8,587	915	11	647	71	458
Puerto Rico (4)	123	22	18	20	91	8
Rhode Island (12)	907	94	10	55	59	57
S. Carolina (1[illegible])	1,555	121	8	82	68	95
S. Dakota (8)	467	72	15	613	85	24
Tennessee (26)	2,406	102	4	98	96	45
Texas (17)	1,595	350	22	287	82	221
Utah (6)	275	10	4	10	1.00	12
Virginia (20)	2,613	303	12	241	80	227
Virgin Islands (1)	15	0	–	–	–	–
Vermont (7)	140	70	50	50	71	41
Washington (44)	1,890	234	12	155	66	250
Wisconsin (40)	3,555	389	11	294	76	296
W. Virginia (12)	586	16	3	13	81	9
Wyoming (2)	110	410	37	26	64	36
Surveys Not Identified by State	1,536	154	10	124	81	76
Totals (1,119)	112,996	12,006	10.6	8,846	73.7%[c]	8,464

[a] The number of surveys returned includes only those which met the survey criteria of providing vocational services to adults with developmental disabilities. See Table 19 for the total response rate, including facilities which did not meet the criteria.

[b] Some states actually may have had a higher rate of retention, since the number retained was counted as zero if this question was left blank.

[c] This percentage is slightly lower than the average of the retention measures reported for each survey, due to the fact that 217 individuals from the detailed survey had not yet worked 60 days.

Impact on Social Security Benefits

The final broad research areas dealt with knowledge and use of Section 1619 (a) and (b) of the Social Security regulations and whether the current emphasis on employment for adults with developmental disabilities impacted a person's Social Security benefits. Facilities receiving the Detailed Survey were asked questions which related to both of these areas. Table 16 reveals that although 61.8 percent of those responding had knowledge of section 1619 (a) and (b), only 24 percent of these facilities had actually used one of the provisions. Finally, there is a clear indication from those responding (95.3 percent) that if this provision were to be made permanent, it would be accessed by even more adults with developmental disabilities as a resource toward achieving greater economic self-sufficiency through employment.

Table 16

Knowledge and Use of Title 1619 A and B (Response per Facility)

Question	Response Category	
	Yes (Percent)	No (Percent)
Knowledge of 1619 A & B?	188 (61.8)	116 (38.2)
Used 1619 A & B?	71 (24.3)	221 (75.7)
More likely to use if permanent?	161 (95.3)	8 (4.7)

Social Security data were also available for most individuals reported in the Detailed Survey. This permitted, among other things, analysis of the impact of employment upon the person's benefit level. These data are summarized in Table 17.

Table 17
Effects on Social Security by Disability Level
(Detailed Survey)

Disability Level	Receives SSI		Receives SSDI		Benefit Level Affected By Job Placement		Accessed 1619			
							A		B	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Severe/Profound	52	6	5	26	12	32	4	22	0	22
Moderate	227	37	34	87	119	85	53	83	31	80
Mild	412	254	94	347	189	170	89	221	75	214
70 or above	164	412	70	399	95	59	27	179	26	171
Totals	855	709	203	859	415	346	173	505	132	487
Percent	54.7	45.3	19.1	80.9	54.5	45.5	25.5	74.5	21.3	78.7

Approximately 55 percent of the persons reported in the survey were receiving Supplemental Security Income (SSI), although the percentage varied according to disability levels. Only 19.1 percent were receiving Social Security Disability Insurance (SSDI), and less than 10 percent of the sample were receiving a combination of SSI and SSDI. Employment placement affected 54.5 percent of the reported sample's benefit levels. However, only 25.5 and 21.3 percent of the sample, respectively, reported accessing Section 1619 (a) or (b).

Discussion

A number of general conclusions can be drawn from the data summarized in the Results Section. First, among the facilities responding, most adults with developmental disabilities are found within sheltered employment environments. However, the data suggest a trend toward increased movement into other employment environments, including transitional training, supported and competitive employment. Second, employment outcomes vary according to disability level and employment environment; higher monetary outcomes are associated with less severe disability levels and more normalized employment environments. Third, most adults with developmental disabilities are likely to be placed into service, bench work, or clerical/sales occupations. Fourth, competitive employment is the most common placement environment, followed by transitional training, and then supported employment. Furthermore, if the placement changes, the person is most likely to return to the environment prior to placement, rather than a second alternative. Fifth, of those receiving Social Security benefits (SSI and/or SSDI-60.9 percent), more than half (54.5 percent) were reported to have their benefits affected as a result of employment. Twenty-five percent of the sample reported that they accessed 1619 (a), and 21.3 percent accessed 1619 (b). And sixth, our benefit analysis indicates that, based on the data obtained, benefits to individuals and society from placement in employment range from $205 million to $280 million annually. Each of these conclusions is discussed in more detail in the remainder of the Discussion Section.

Current Employment Services Pattern

Data summarized in Table 2 indicate that 57.6 percent of adults with developmental disabilities were in sheltered employment. However, from Oct. 1, 1984 to Sept. 30, 1985, the responding agencies, organizations, and/or facilities placed 10.6 percent of their clientele into competitive employment, 5.6 percent into transitional employment, and 3.7 percent into supported employment. This 19.9 percent total placement rate is higher than that reported either in the previous survey by Kiernan and Ciborowski in 1985 or by Whitehead in 1981. It is important to note that this increase is due to the two employment placement environments (transitional and supported) that were not included in the previous studies. It is interesting to compare the 10.6 percent placement into competitive employment found in the current study with the 8 percent reported by Whitehead (1981) and the 12.6 percent reported by Kiernan and Ciborowski (1985). A possible implication is that we can increase placements by implementing placement environments other than competitive, e.g., supported and transitional training.

Most facilities providing sheltered employment also provided competitive employment placement, but fewer than half provided either transitional training or supported employment (see Table 3). The trend from 1983-84 to 1984-85, however, was to increase placements into a wider variety of employment environments. For example, as indicated in Table 6, there was an 87 percent increase in transitional training placements, a 74 percent increase in supported employment placements, and a 58 percent increase in competitive employment placements for the facilities surveyed during the two-year period. The increase was due primarily to the relative increase in part-time placements from 1983-84 to 1984-85, especially for transitional and supported employment (see variable #5, Table 6).

One purpose of this survey was to determine the relationship between facility size and placement activities. These data were summarized in tables 3 and 4. Several trends are apparent in these data. First, there is an inverse linear relationship between facility size and the percent of persons served within that agency who are developmentally disabled; that is, a greater proportion of clientele in smaller facilities are developmentally disabled than in larger facilities. Second, the majority of facilities either are in the 1-75 size range or are larger than 200. Third, of the 1,115 facilities reporting size data, 76 percent provided sheltered employment, 71 percent provided competitive employment placement, 37.9 percent provided transitional training/employment placement, and 32.6 percent provided supported employment placement. The smaller percentage of transitional and supported employment services, coupled with the fact that these two relatively new employment options have increased the total percentage of individuals entering real work environments, create a strong argument for their expanded development (see Mank, Rhodes & Bellamy, 1986, for a discussion of alternative employment environments). And in a fourth trend, the placement rate data presented in Table 4 suggest that facilities in the 1-25 and 151-175 size categories are most effective at placement, in that they placed approximately one-third of their clients into one of the employment environments during the one-year period.

The smaller facilities may tend to be single-focused agencies, more effective in accomplishing their mission and, thus, more efficient. It is also possible that such agencies are more precise in their selection criteria. Because no cost data were collected, little can be said about how cost effective smaller organizations are and whether there are economies of scale that may only be achieved through association with a larger structure. These questions cannot be answered by the current survey. However, they need to be examined in the future, particularly for planning purposes and for designing administrative structures capable of accessing greater employment opportunities for individuals with severe disabilities.

Employment Outcomes

Evaluation of the employment outcomes summarized in tables 6 and 8 depends upon the outcome measure selected and the comparison made. For example, competitive employment wages (averaged for full and part time; Table 6) averaged $3.86 per hour (a 7.0 percent increase from the $3.69 per hour reported in the 1983-84 survey conducted by Kiernan and Ciborowski), compared with $2.59 for supported employment and $2.37 for transitional employment. Hours per week varied significantly among these three environments, averaging 27.3 for transitional training, 25.3 for supported employment, and 33.8 for competitive employment (Table 6; average of full and part time). Employment outcomes varied by disability level, but the significance depended upon the outcome measure analyzed (see Table 8). For example, starting wages for persons with above 70 IQ's were 28 percent higher than those diagnosed in the severe/profound range and about 15 percent higher than those diagnosed in the mild or moderate ranges. The average hours worked per week, however, increased linearly as the level of disability decreased. The number of weeks worked since placement differed only for the severe group.

The major implication from these employment outcomes is that many severely or moderately disabled persons can be gainfully employed, even though they might work fewer hours per week than less disabled persons. This finding is consistent with those reported by numerous investigators, and it lends support to the current emphasis on regular employment opportunities for adults with developmental disabilities (Kiernan & Stark, 1986; Rusch, 1986). A second implication is that multiple employment outcome measures should be used to describe adequately the effectiveness and efficiency of employment programs, because one derives a slightly different picture depending upon the measure(s) analyzed.

The outcome data regarding sheltered employment for 65,093 persons were summarized in table 5 and 5B according to employment status, hours worked, wages and percentile comparisons. Thirty-two percent were employed full time, earning $1.47 an hour, while 68 percent were employed part time, earning an average of $1.24 per hour. Furthermore, 25 percent of these individuals were earning less than $0.75 per hour, 50 percent less than $1.09, and 75 percent less than $1.67. The average hourly wage obtained in both surveys represents an absolute increase from that reported in earlier studies by Whitehead (1979), Schalock (1983) and the University of Oregon (1983). However, when analyzing earnings in relation to minimum wage, 50 percent of the population in sheltered employment continue to earn about 32.5 percent of the current minimum wage (3.35 per hour). It is felt that the current data reflect the status of sheltered employment outcomes more adequately than those that were reported previously. These data also suggest the need for programs to report individual outcome data so that appropriate measures of average earnings, range of earnings and variability in earnings can be obtained.

To conclude this section, the issue of employment outcomes is intricately related to the way one defines job retention. The definition used in the General Survey was the 60-day criteria utilized by the Rehabilitation Services Administration (RSA). This relatively short period has been used by RSA for many years as the indicator of a successful job placement. The data showed a competitive employment retention rate of 77.4 percent for this 60-day period. A longer time-period was utilized to measure retention in the Detailed Survey, yielding an average rate of 72.8 percent over a 22-week period. Both of these rates are consistent with the 60-day retention outcomes reported by Kiernan and Ciborowski in 1985 (76.5 percent for full time and 74.2 percent for part time). It should be noted that the literature on the subject reports considerable variation in retention rates based on definition, population, and duration. The authors consider the retention rates quoted here to be sound and use them in projecting a range for the benefit analysis reported later in this section.

Occupational Categories

A unique aspect of the survey was the classification of all job placements according to one-, two- and three-digit categories in the Dictionary of Occupational Titles. This allowed for a more detailed analysis of placement data than was previously available, and it provided the opportunity to relate these data to present and future employment trends. As shown in Table 9, 68 percent of the placements were represented by three occupational categories, service, clerical-sales and benchwork, for both the Detailed and General surveys. These occupational categories are frequently reported as high placement areas for persons with disabilities. However, when one refers to the two- and three-digit codes (see tables 10 and 12), it becomes apparent that persons with developmental disabilities are placed into a wider variety of jobs than previously reported. These data should encourage job placement personnel to seek out widely disparate job placements and not be constrained by the stereotyped job categories into which disabled persons are frequently placed.

The data utilizing job categories also provide an opportunity to consider, from a strategic planning orientation, accessing job categories which have a high demand projected for the future. From supply-and-demand perspectives, it is imperative that agencies know what is needed in the market place and direct their training efforts to meet those needs. The U.S. Department of Labor's Employment Projections for 1995 (1984) presents the high growth occupations for the next 10 years. These projections show a number of occupations in which there will be a continuing demand (Table 18). Some of these occupations are consistent with current placement efforts, while others reflect potential future employment opportunitites for adults with developmental disabilities. It is projected that occupations such as guards and doorkeepers, helper trades, stock clerks, and delivery persons will have increased demand and, thus, suggest opportunities for the future.

Table 18
Occupations with Largest Growth Rates Employment Projections for 1995

Occupation	Change in Total Employment (in thousands)	Percent of Total Job Growth	Percent Change
Building Custodian	779	3.0	27.5
Cashiers	744	2.9	47.4
Secretaries	719	2.8	29.5
General Clerical	696	2.7	29.6
Salesclerks	685	2.7	23.5
Nursing Aids	423	1.7	34.8
Guards and Doorkeepers	300	1.2	47.3
Food Preparation and Service Workers (Fast Food)	297	1.2	36.7
Helpers, Trades	190	.7	31.2
Stock Clerks, Stockroom and Warehouse	156	.6	18.8
Delivery and Route Workers	153	.6	19.2

Note: Includes only occupations with 1982 employment of 25,000 or more, with data for 1995 based on Department of Labor moderate trend projections.

Source: U.S. Department of Labor, Bureau of Labor Statistics, Employment Projections for 1995, March 1984 (Bulletin 2197)

An interesting association between job placement category and disability level is suggested in the data summarized in Table 11. The trend seems to be that, as one might expect, the number of potential job placement categories increases as the level of disability decreases. For example, despite the small sample size, 86 percent of those with severe retardation were placed into service or benchwork jobs; individuals in the moderate group were placed primarily into service-related jobs, but also were placed into clerical/sales, agriculture-forestry and benchwork; and mildly disabled persons as well as those with IQs above 70, were placed into these same categories, plus structural work and machine trades.

Hopefully, subsequent studies on employment outcomes will continue to use a standardized job classification system in order to obtain better longitudinal data on the employment patterns and differential success rates across job categories. For example, a recent study by Schalock, Wolzen, Ross, Elliott, Werbel and Peterson (in press) reported the following five year job retention rates for special education graduates in Nebraska according to job categories: agricultural services (88 percent retention), farm related work (69 percent), food and hotel services (59 percent), retail trade (38 percent), and manufacturing (37 percent). The fact that these rates vary considerably across job categories suggests the need for improved person-environmental analysis during the job placement process (Schalock & Lilley, 1986).

Movement Patterns within Employment Statuses

Table 13 summarized the movement patterns within employment statuses, including: the setting prior to placement, the employment environment into which the person was placed, and the current employment environment. Prior to placement, 45 percent of those persons who were later placed were in sheltered employment, 31 percent were unemployed, 18 percent were in transitional employment, 4 percent were already in a competitive job (but would change statuses during the study period), and 2 percent were in supported employment. The primary movement pattern was placement into competitive employment, with less placement into supported or transitional employment. This trend is consistent with the data discussed earlier and it further documents the preference for initial placement into competitive employment. It may also reflect the "newness" of the supported employment designs, as well as the relatively new concept of transitional training employment. The rate of growth in these two areas is greater than that reported for competitive employment, revealing that in the years to come there should be considerable expansion of these employment options. By far the most frequent comment in the narrative portion of the survey responses noted plans to add supported employment to the range of services offered by many agencies.

In examining the current employment environment (Table 13, right column), other trends are suggested. Specifically, the percent of persons in transitional status decreased, as did the percent in competitive employment. The percent in supported employment remained essentially the same, suggesting minimal attrition or movement. About 10 percent returned to sheltered employment, and 14 percent became unemployed. These movement patterns are important to facility directors and policy makers because of what they indicate about clients who return to the program, the support necessary to maintain a person's employment status, and the continued high unemployment rates one might expect, even after initial and/or repeated job placements (Schalock & Lilley, 1986; Wehman et al., 1985).

Data were also available in the Detailed Survey that permitted analysis of the movement patterns by disability levels (see Table 14). These movement patterns differ somewhat, depending upon the disability level. In reference to placement environment (Table 14, column 2), individuals labeled severe/profound were placed rather evenly into the three employment environments; whereas for the other three groups, preference was given to competitive employment. An expected trend is seen, wherein supported employment was used less frequently with less severe disabilities, with the converse being true for competitive placement. Transitional employment was used about equally for the moderate and mild groups, and less for those with with IQ's above 70. These trends are predictable, given the current emphasis on supported employment for those who are more severely disabled (Bellamy, Rhodes & Albin, 1986). In reference to the current environment, the highest percentage of current placement across the four groups was competitive employment, with the percentages for the other employment statuses varying depending on the disability level.

Impact on Social Benefits

Recently, there has been considerable discussion regarding the disincentives to work contained in the Social Security regulations and the anticipation that use of Sections 1619(a) and (b) should reduce these disincentives (Conley, Noble & Elder, 1986). With this issue in mind, the investigators included questions on the Detailed Survey that would help clarify the disincentives issue and the impact of Sections 1619 (a) and (b). These data are presented in tables 16 and 17. Table 16 shows that 38 percent of the reporting facilities had no knowledge of 1619 (a) and (b). Alarmingly, nearly 76 percent had not used these provisions, but 95 percent indicated that they would be more likely to use them if they were made permanent. When the provisions were utilized, 1619 (a) was used slightly more (25.5 percent) than (b) (21.3 percent). These findings have important implications for policy makers, particularly with respect to extending 1619 (a) and (b). Job placement was reported to affect 54.5 percent of the sample's SSI/SSDI benefit levels. The effect was reported most frequently for those with IQ's of 70 and above (62 percent) and least frequently for those diagnosed in the severe/profound category (27 percent). Individuals with moderate and mild mental retardation were reported at 58 and 53 percent, respectively. This finding clearly indicates a potential disincentive to employment, but calls for additional study and more general use of 1619 (a) and (b) before definitive statements can be made regarding disincentives.

Benefit Analysis

A number of benefits for the individual and society can be calculated, as a result of the data received and estimates based upon a full-sample response. Actual data from surveys received and from telephone interviews (total contacts: 74.5 percent of the full sample, see Table 19) resulted in a projection that 2,506 agencies, facilities, and organizations would meet the criteria of providing vocational services to adults with developmental disabilities. This estimate reflects:

- –those who responded to both the general and detailed surveys indicating that they met the criteria (1,119),
- –those contacted by telephone who indicated that they provided vocational services to adults with developmental disabilities (720), and
- –of the 801 non-respondents not contacted, an estimate that 667 would meet the criteria (the same percent, 83.3, as those contacted by telephone who met the survey criteria).

Table 19

Sample Response Rates and Phone Contacts by State and Territory (General and Detailed Surveys)

State or Territory	Sent	Respondents[a]	Percent Responding	Nonrespondents Contacted By Telephone	Total Percent Responding & Telephone Contacts
Alaska	7	3	43	4	100
Alabama	27	12	44	12	89
Arkansas	38	18	47	15	87
American Samoa	1	1	100	0	100
Arizona	24	14	58	7	88
California	329	132	40	168	91
Colorado	46	15	33	11	57
Connecticut	69	34	49	11	65
Delaware	5	4	80	1	100
D.C.	16	6	38	1	44
Florida	94	47	50	25	77
Georgia	58	20	35	29	85
Hawaii	16	9	56	3	75
Iowa	59	41	70	5	78
Idaho	14	7	50	6	93
Illinois	103	37	36	8	44
Indiana	73	38	52	8	63
Kansas	33	22	67	4	78
Kentucky	40	21	53	19	100
Louisiana	48	20	42	24	92
Massachusetts	66	35	53	13	73
Maryland	51	27	53	10	73
Maine	32	15	47	5	63
Michigan	115	54	47	23	67
Minnesota	145	79	55	28	74
Missouri	56	29	52	8	66
Mississippi	36	16	44	20	100
Montana	32	19	59	3	69
North Carolina	66	26	39	28	82
North Dakota	18	9	50	0	50
Nebraska	39	24	62	9	85
New Hampshire	30	9	30	6	50
New Jersey	100	45	45	26	71
New Mexico	29	13	45	10	79
Nevada	16	9	56	5	88
New York	215	105	49	33	64
Ohio	62	21	34	10	50
Oklahoma	70	35	50	24	84
Oregon	69	33	48	34	97
Pennsylvania	143	72	50	23	66
Puerto Rico	15	8	53	2	67
Rhode Island	28	14	50	9	82
South Carolina	34	14	41	17	91
South Dakota	19	8	42	3	58
Tennessee	72	33	46	32	90
Texas	62	23	37	33	90
Utah	19	7	37	0	37
Virginia	83	24	29	10	41
Virgin Islands	2	1	50	0	50
Vermont	18	9	50	4	72
Washington	111	53	48	43	87
Wisconsin	110	54	49	27	74
W. Virginia	39	15	38	3	46
Wyoming	4	2	50	2	100
Surveys Not Identified By State	31	31	N/A	N/A	N/A
Totals	3,137	1,472	47%	864	74.5%

[a] This number includes respondents who indicated they do not provide vocational services to adults with developmental disabilities, unlike Tables 2 and 17, which are limited to facilities meeting the survey criteria.

Based upon the General Survey data only showing a placement rate of 13.9 in full-time and 9.8 in part-time supported, transitional training or competitive employment, a total of 62,409 adults with developmental disabilities were estimated to be placed into employment (supported, transitional training, and/or competitive) during the 12-month survey period. In light of the 74.5 percent contact rate, this estimate appears to accurately reflect the total number of persons placed in the full sample The following projections of benefit associated with employment are based upon this estimate.

The benefit analysis presents the benefits to the individual and society and are grouped into four categories: annual tax contribution, transfer payment reduction, reduction in alternative program costs, and Social Security contributions. Table 20 presents high- and low-range estimates for the benefit analysis. These ranges reflect the different retention rates. The higher range is based upon a 77.4 percent retention rate for a 60-day period as reported in the General Survey, while the lower range uses a 72.8 percent rate for a 22-week period as reported in the Detailed Survey. All estimates of benefits are adjusted for retention. When using the high estimate (retention rate of 77.4 percent), it can be anticipated that 48,305 individuals will remain on the job. Applying the more conservative estimate (72.8 percent), 45,434 persons would remain employed. These estimates of individuals remaining on the job serve as the basis for benefits presented in Table 20.

Table 20

Annual Estimated Benefits
Through Employment
for Adults with Developmental Disabilities

(Estimates based upon 62,409 adults)

	Range of Estimate	
	High	**Low**
Estimated total annual earnings	**$250,252,034**	**$235,379,179**
A. Annual Tax Contribution		
Taxes Paid by Individual		
Federal	12,712,443	11,961,618
State	9,018,662	7,598,908
Taxes Paid by Industry		
Federal Unemp.	2,002,016	1,883,033
State Unemp.	10,510,585	9,885,925
Total Taxes Paid	34,243,706	31,329,484
B. Transfer Payment Reduction		
Reduction in SSI		
Participation rate 54.7% or Participation rate 75%	45,332,340 to 62,155,859	42,657,731 to 58,488,663
C. Reduction in Alternative Programs Costs		
Participation rate 70.1% or Participation rate 100%	104,022,222 to 148,391,187	97,884,912 to 139,636,108
D. Social Security Contribution		
By the Individual	17,893,020	16,829,611
By Industry	17,893,020	16,829,611
Total Social Security Paid	$ 35,786,040	$ 33,659,222
Range of Total Estimated Benefits	$219,384,308 to $280,576,792	$205,531,349 to $263,113,477

The projected gross earnings, applying the high range, are estimated to be more than $250 million for a 12-month period. Using the low range, the projected gross earnings for 12 months are more than $235 million. These estimates reflect earnings from both part-time and full-time supported, transitional training, and competitive employment, based on actual data from the General Survey.

The annual tax contribution for each range is also presented. The federal tax contribution is based upon the actual earnings for all types of employment (full- and part-time), using the tax tables for fiscal year 1985. The state tax contribution reflects the average state income tax obtained from the State Tax Handbook (Commerce Clearing House, 1985). No adjustments were made for sales or use taxes. The federal unemployment tax (.8 percent) and the state unemployment tax (average 4 percent) are based upon wages paid.

Transfer payment reductions reflect the reduction in Social Security payments made to individuals whose earnings exceed the allowable amount. This estimate presents a range of potential savings reflecting different participation rates. From the data received in the Detailed Survey, 54.7 percent of the individuals were reported to be receiving Supplemental Security Income (SSI). Schalock (1986) reported a 75 percent rate of SSI enrollment in a follow-up study in Nebraska. These participation rates provide a range for estimating savings in SSI benefits through employment. Using the average monthly payment for SSI ($258.66 for the month of December 1984) and adjusting for earnings from all types of employment (reducing benefits paid by a one for two ratio), the estimated reduction in SSI payments ranged from a high of $62 million to a low of $42.6 million annually. These estimates assume that individuals would be eligible for 1619 (a) and that they are already at a one-half reduction point due to their level of earnings. (According to Social Security regulations, the first $20 of earned or unearned income per month and the next $65 per month are not used to reduce the amount paid to the recipient.)

The reduction in alternative program costs shows the savings realized from some individuals no longer being in a day- or sheltered-employment setting but, rather, in employment. Again from the Detailed Survey data, 70.1 percent of those placed were in day- or sheltered-employment programs prior to being placed into transitional training, supported or competitive employment. It is believed that all individuals reported in the survey could be considered eligible for day- or sheltered-employment settings, although they may not have wanted to attend or may not have had the opportunity. Thus, it was felt that a range reflecting full participation (100 percent) and the 70.1 percent participation rate was appropriate to use in estimating alternative-program cost savings. The estimated cost for day- or sheltered-employment programs was $18.50 per day (Buckley & Bellamy, 1985). The estimated savings in this category were adjusted for full-time and part-time status, assuming that approximately half of the individuals in a part-time employment status would continue to be involved in some other type of part-time day program; thus, the savings from these individuals would be less.

The last benefit listed could be considered more a benefit to the individual than to society. It reflects the contribution to Social Security by both the individual and the industry in proportion to earnings (7.15 percent). This contribution ranges from $17.8 million to $16.8 million annually. As is the case with all workers who contribute to Social Security, this is viewed as a form of retirement and will yield a return to the individual when he/she retires. Such a future return likely will reduce the amount of public monies required to support the adult with developmental disabilities in retirement and, thus, will be a future benefit to society.

Applying the high estimate (retention rate of 77.4 percent), the benefits derived through annual tax contributions, reduction in transfer payments, reduction in alternative program costs and contributions to Social Security ranged from more than $280 million to $219 million for a 12-month period. Using the more conservative retention estimate (72.8 percent), the benefit ranged from $263 million to $205 million for the same period.

Conclusions

It is clear there are many benefits realized by the individual and by society when employment opportunities are provided for adults with developmental disabilities. These benefits include tax revenue (income as well as sales and other usage taxes), reduction in alternative program costs, and reduction in dependency on third-party supports. However, these obviously are not the only benefits realized through employment. Industry realizes gains of increased production and reduced job turnover costs when there is a good match between the worker's abilities and the demands of the job. Society realizes economic and humanitarian gains by having a contributing member, rather than a dependent one. The adult with developmental disabilities also realizes gains through increased disposable income, improved quality of life and an increased sense of self-worth.

From all perspectives, the increased emphasis on and activity within employment placement makes good sense, economically, socially, and emotionally. The movement to create employment opportunities for adults with developmental disabilities is one which has broad-based support and one in which there should be continued investment from government, industry, professionals, parents and the adult with developmental disabilities.

Appendix

Definitions to Be Utilized in Survey

Developmental Disabilities

A developmental disability:

- is a chronic disability attributable to a mental or physical impairment or both
- is manifested **before the age of 22**
- is likely to continue indefinitely
- results in substantial limitation in three or more of the following areas of life activity: self care, receptive and expressive language, learning, mobility, self direction, capacity for independent living, or economic self sufficiency
- reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of life-long or extended duration.

Employment Status

a) **full-time:** employed 35 hours per week or more

b) **part-time:** employed less than 35 hours per week

Employment Service Options

a) **sheltered employment** - employment in a controlled environment, where payment is typically at **less than** the minimum wage

b) **transitional training/employment** - employment which provides **time-limited support** leading to competitive employment (may include work/employment training stations, on-the-job training, or enclaves), where payment is typically at **less than** the minimum wage

c) **supported employment** - employment which requires **intensive ongoing support,** utilizing work sites where persons without disabilities are employed, where payment is **most often at less than** the minimum wage

d) **competitive employment** - unsubsidized employment where payment is **at or above** the minimum wage (including certain enclaves, work crews, and employment in regular jobs even when follow along services are provided)

SOCIAL SECURITY 1619 (a); 1619 (b)

a) **1619 (a);** a special provision which protects and continues the SSI cash payment of a disabled recipient whose work above the SGA level would normally end basic SSI eligibility, even though he or she remains severely impaired.

b) **1619 (b);** a special provision which assures Medicaid coverage to individuals who lose their SSI payments due to their earnings but, who, nonetheless, need continued Medicaid coverage to work.

November 25, 1985

Dear Colleague:

During the past two years, much emphasis has been placed upon expanding employment opportunities for disabled persons. The Administration on Developmental Disabilities, through its Employment Initiative, has attempted to increase employment opportunities for the adult with developmental disabilities.

A National Survey of Employment of Adults with Developmental Disabilities was conducted last year by the Developmental Evaluation Clinic, a University Affiliated Facility at Children's Hospital in Boston, MA. The data received were extremely helpful in reviewing employment trends and in providing policy makers and administrators with information for program development and fiscal planning.

We are again asking you to assist us in documenting the ongoing movement of adults with developmental disabilities into employment. The enclosed survey will help verify the expanding role you are continuing to play in facilitating the employment effort. The survey should take thirty to sixty minutes to complete. It is not necessary to have responded to last year's survey to participate in this one. A greater response will improve the reliability of the findings and enhance their use for program planning purposes. All respondents will receive a summary of the survey results. Due to the national scope of the survey, this data will be helpful in your program planning and development activities.

The definitions found on the enclosed sheet should be utilized in completing the survey form. If none of the persons served is considered developmentally disabled, please answer question one and return this form to us. It is extremely important that we know this information as well as the placement information. If any persons served are developmentally disabled, please return this survey in the enclosed envelope by December 15, 1985. If you have any questions, feel free to contact me or Martha McGaughey at (617) 735-6506 or at the above address.

Thank you for providing us with this most valuable data.

Sincerely,

William E. Kiernan

William E. Kiernan, Ph.D.
Director of Rehabilitation

SURVEY

EMPLOYMENT OF ADULTS WITH DEVELOPMENTAL DISABILITIES

Name of Organization:
Address:
City/State/Zip Code:
Telephone Number:

Name of Person Completing Survey:

I would be interested in receiving the summary of this survey ______ yes ______ no

Utilizing the attached definitions for reference, please answer all questions as accurately as possible.

QUESTIONS 1 - 7 REFER TO PERSONS SERVED FROM 10/1/84 TO 9/30/85.

1. To how many persons did your organization provide vocational services from October 1, 1984 to September 30, 1985? ______________
   a) Of that number, how many would by definition be considered developmentally disabled? ______________
   b) If **no** adults with developmental disabilities were served, check here. ______________
   c) If you serve adults with developmental disabilities but do not provide any vocational/employment services, check here. ______________

If either b) or c) is checked above, please return this survey now. If they are not checked, please continue.

2. Within the same time period, how many adults with developmental disabilities were placed in:

	Full-time	Part-time
transitional training/employment	____________	____________
supported employment	____________	____________
competitive employment	____________	____________

3. How many adults with developmental disabilities, placed in competitive employment from 10/1/84 to 9/30/85, remained on the job for more than 60 days?

Full-time	Part-time
____________	____________

4. Of those adults with developmental disabilities placed from 10/1/84 to 9/30/85, what is the:
   a) average (mean) age of the time of placement in:
      transitional training/employment __________ years of age
      supported employment __________ years of age
      competitive employment __________ years of age
   b) age range (youngest to oldest) at time of placement in:
      transitional training/employment ______ years to ______ years
      supported employment ______ years to ______ years
      competitive employment ______ years to ______ years

5. Of those adults with developmental disabilities who were placed in employment from 10/1/84 to 9/30/85, at the time of placement what was:

	Full-time	Part-time
a) the average wage per hour for:		
transitional training/employment	$ ______/hr	$ ______/hr
supported employment	$ ______/hr	$ ______/hr
competitive employment	$ ______/hr	$ ______/hr
b) the average number of hours worked per week in:		
transitional training/employment	______hrs/wk	______hrs/wk
supported employment	______hrs/wk	______hrs/wk
competitive employment	______hrs/wk	______hrs/wk

6. If you are providing a sheltered employment setting for adults with developmental disabilities:

	Full-time	Part-time
a) How many were served from 10/1/84 to 9/30/85?	______	______
b) What is the average wage per hour?	$ ______/hr	$ ______/hr
c) What are the average hours worked per week?	______hrs/wk	______hrs/wk

7. Please list the types of full and part-time competitive jobs in which adults with developmental disabilities were placed and the number of placements for each.

Title	Number Placed
______	______
______	______
______	______
______	______
______	______
______	______
______	______

8. Within the time period **10/1/83 to 9/30/84,** how many adults with developmental disabilities were placed in:

	Full-time	Part-time
transitional training/employment	______	______
supported employment	______	______
competitive employment	______	______

Please use the space below for any additional comments. Thank you.

November 25, 1985

Dear Colleague:

During the past two years, much emphasis has been placed upon expanding employment opportunities for persons with disabilities. The Administration on Developmental Disabilities, through its Employment Initiative, has attempted to increase employment opportunities for the adult with developmental disabilities.

A National Survey of Employment of Adults with Developmental Disabilities was conducted last year by the Developmental Evaluation Clinic, a University Affiliated Facility at Children's Hospital in Boston, MA. The data received were extremely helpful in examining employment trends and in providing policy makers and administrators with valuable information for program development and fiscal planning.

We are again asking you to assist us in documenting the movement of adults with developmental disabilities into employment. **An essential component of this second survey is the collection of individual data on persons whom you have placed during the survey period, (October 1, 1984 to September 30, 1985).** While this second survey will take more time to complete, the data received will be of substantial value in looking at the benefits and costs of employment for these adults. With your help, we also hope to examine issues of employment retention and job mobility. It is not necessary to have responded to last year's survey to participate in this one. A greater response will improve the reliability of the findings and enhance their use for program planning purposes. All respondents will receive a summary of the survey results. Due to the national scope of the survey, this data will be helpful in your program planning and development activities.

The definitions found on the enclosed sheet are to be utilized in completing the survey form. The survey should take about fifteen minutes per person placed. If none of the persons served is considered developmentally disabled, please answer question one and return the form to us. It is extremely important that we know this as well as the placement information. If any persons served are developmentally disabled, please complete and return the survey in the enclosed envelope by December 15, 1985. If you have any questions, feel free to contact me or Martha McGaughey at (617) 735-6506 or at the above address.

Thank you for providing us with this most valuable data.

Sincerely,

William E. Kiernan

William E. Kiernan, Ph.D.
Director of Rehabilitation

EMPLOYMENT SURVEY OF ADULTS WITH DEVELOPMENTAL DISABILITIES

Name of Organization:
Address:
City/State/Zip Code:
Telephone Number:
Name of Person Completing Survey:

I would be interested in receiving the summary of the survey findings _____ yes _____ no

Utilizing the enclosed definitions please answer and complete the individual data survey as accurately as possible.

1. From October 1, 1984 to September 30, 1985, how many persons did your organization provide vocational services to? _____________
   a) Of those served, how many would by definition be considered developmentally disabled? _____________
   b) If **no** adults with developmental disabilities were served, check here. _____________
   c) If you serve adults with developmental disabilities but do not provide any vocational/employment services, check here. _____________

If either b) or c) are checked above, please return this survey now. If they are not checked, please continue.

2. If you are providing a sheltered employment setting (see definition) for adults with developmental disabilities:

	Full-time	Part-time
a) How many were served from 10/1/84 to 9/30/85?	___________	___________
b) What was the average wage per hour?	$ _______/hr	$ _______/hr
c) What were the average hours worked per week?	_____hrs/wk	_____hrs/wk

3. Within the time period **10/1/83 to 9/30/84**, how many adults with developmental disabilities were placed in:

transitional training/employment	___________	___________
supported employment	___________	___________
competitive employment	___________	___________

4. Do you have any knowledge of 1619 (a) and (b)? _______ yes _______ no

5. Have you used 1619 (a) or (b)? _______ yes _______ no

6. If 1619 (a) and (b) were permanent, would your employees be more likely to use this? _______ yes _______ no

If no is checked in questions 4 and 5 above, skip the columns entitled "1619 (a), 1619 (b)" on the questionnaire.

On the reverse side, please indicate each individual using ID numbers, starting with 1. **Each row should reflect a specific placement** made during the time period 10/1/84 thru 9/30/85. For persons with more than one placement, use the same ID number for the individual and a separate letter and row to indicate each placement (see example below). Use the letters in the key at the bottom to complete the appropriate columns.

Example:	**ID Number**	**Job Title**
(Jones)	1 (a)	Dishwasher
(Jones)	1 (b)	Cleaning

EMPLOYMENT OF ADULTS WITH DEVELOPMENTAL DISABILITIES

Survey Period: October 1, 1984 to September 30, 1985

ID Number	1	2	Individual Characteristics			Employment Data			Job Title Placed In	4 Social Security					5
	Setting Prior to Placement	Placed Into	Date of Birth	— Gender	3 Disability Level	Starting Wages Per Hour	Average Hours Per Week	Wks. worked Since Placement		Receives		Benefit Level Affected By Employment?	Accessed		Current Employment Environment
										SSI	SSDI		1619 (a)	1619 (b)	

1. Setting Prior to Placement

A. Transitional/Training Employment
B. Supported Employment
C. Competitive Employment
D. Sheltered Employment
E. Unemployed

2. Placed Into

A. Transitional/Training Employment
B. Supported Employment
C. Competitive Employment

3. Disability Level by IQ

A. IQ 24 (profound)
B. IQ 25-39 (severe)
C. IQ 40-54 (moderate)
D. IQ 55-69 (mild)
E. IQ 70 or above

4. Social Security Possible Choices

Y. yes
N. no

5. Current Employment Environment

A. Transitional/Training Employment
B. Supported Employment
C. Competitive Employment
D. Sheltered Employment
E. Unemployed

December 23, 1985

Dear Colleague:

Several weeks ago, we sent you a copy of the National Survey of Adults with Developmental Disabilities Entering Employment to complete. Because we have not yet received your response to this critical study, another questionnaire is enclosed.

The data you provide to this study will assist us in documenting the movement of adults with developmental disabilities into employment as well as in analyzing information on job mobility and employment retention. These data will also be crucial to national policy makers and administrators in their program development and fiscal planning activities.

Due to the significant policy implications of this study, it is hoped that you will take time to provide this information as soon as possible. All respondents will receive a summary of the survey results, which will be beneficial to your program planning and development activities.

If none of the persons you serve is considered developmentally disabled or if you do not provide vocational/employment services, it is still extremely important to the data analysis that you answer question #1 and return this form.

Thank you for your time. We look forward to receiving your response within the next week.

Sincerely,

William E. Kiernan

William E. Kiernan, Ph.D.
Director of Rehabilitation

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Senator STAFFORD. Thank you very much.

Thank you, Mr. Chairman.

Dr. ELDER. You are welcome.

Senator HARKIN. Thank you very much, Senator Stafford.

I just want to respond again to the kind words of my good friend, Lowell Weicker. I want again to thank you and also Senator Stafford for your many kindnesses and for your help in helping me to get a grasp on this Subcommittee, and to also publicly thank your staff. They have just been great in working with us, and I really appreciate it very much.

Dr. Elder, just a couple final ones. When can we expect final regulations on the Developmental Disabilities Act?

Dr. ELDER. Let me get my notes so I get the dates right. The NPRM for all four of our programs was published in the Federal Register July 17th of 1986. Then we had a 60-day comment period, which takes us to September 15th of 1986.

I want to back up a minute, to remind us that these new regulations establish program standards for University-Affiliated Facilities. We therefore took a little bit more time than usual.

The 60-day comment period took us to September 15, 1986. All the comments received were incorporated and we have a draft final rule. The draft final rule has gone through preliminary departmental clearance and now we are going through final departmental clearance.

I am pushing for these regulations. I follow their progress from desk to desk. I want them out as quickly as you do. We have not had regulations since August 6, 1979 for the UAF program, so it is important that we get these regulations.

Also know that we have issued many policy issuances in the Administration on Developmental Disabilities in that interim to make certain that the States are as well informed as possible.

Senator HARKIN. And there is the April 1st annual report?

Dr. ELDER. The April 1st annual report has cleared the Office of Human Development Services.

Senator HARKIN. Thank you very much.

Let me recognize now Senator Simon for any opening statement.

Senator SIMON. Thank you, Mr. Chairman.

I would like to put an opening statement in the record, and I apologize for not being here for the testimony.

Let me just add, since this is the first meeting of the Subcommittee, that Lowell Weicker, your predecessor, has not only been there with his head, but he has been there with his heart, fighting for the good cause, and I really appreciate it, and he has had the cooperation of Senator Stafford. But I would say to the community that is concerned, and as one who chaired the Subcommittee in the House for two years with concern in this area, Tom Harkin has the same kind of bulldog tenacity in fighting for the things he believes in, and he is going to be a fighter for people with disabilities just as Lowell Weicker has been, and I am proud to be associated with all three of you.

Senator HARKIN. Thank you very much.

Senator WEICKER. Thank you, Senator Simon.

Senator SIMON. If I could just add—and it has nothing, but in a sense, it has everything to do with this, but in a sense is not directly related to your report here—I just learned the other day that the unemployment rate among employable blacks with disabilities is 82 percent, and the average income for the 18 percent who are working is just under $4,000. Now, that tells you we have a long way to go yet in our society.

Senator HARKIN. Thank you very much, Paul, for that observation.

Dr. Elder, thank you very much for your testimony.

Dr. ELDER. Thank you all very much.

Senator HARKIN. Our next panel will consist of Lynn Wasick of Highland, Michigan; Raymond Kilroy of Unionville, Connecticut, and Dolores Everitt from Lincoln, Nebraska, if you could all come to the witness table.

I understand that Lynn Wasik, you are accompanied by Robin Friedman, of the Michigan Protection and Advocacy Agency; and Todd Kilroy is accompanied by George Ducharme.

Thank you all for agreeing to testify today. We will just take it in the order that I have it here, so Lynn Wasik, I would like to call upon you first, if I might, from Highland, Michigan, for your testimony. And without objection, all of your testimony will be made a part of the record in its entirety. I would ask you if you could to just sort of briefly summarize your testimony for us.

STATEMENT OF LYNN WASIK, HIGHLAND, MI, ACCOMPANIED BY ROBIN FRIEDMAN, MICHIGAN PROTECTION AND ADVOCACY AGENCY; DOLORES EVERITT, LINCOLN, NE, AND RAYMOND KILROY, UNIONVILLE, CT, ACCOMPANIED BY GEORGE DUCHARME, NORTH GRANBY, CT

Mrs. WASIK. Mr. Chairman, I want to thank you for the opportunity to testify before the Members of this Subcommittee.

My statement is a summary of the larger written testimony that you have before you. I am Lynn Wasik of Highland, Michigan, here today to tell you about my son David.

David is 15 years old, and he has had developmental disabilities since birth. David has been diagnosed as having cerebral palsy, affecting his ability to use his arms or legs; mental retardation, the extent of which has been difficult to determine, since David cannot communicate by traditional means; and has a seizure disorder that requires medication.

Until David was 13 years old, he lived at home with my husband Dennis, his younger brother Steven, and myself. At that time, a series of respiratory problems, an inability to continue to eat food orally, and weight loss forced David into the hospital. He received a tracheotomy to relieve breathing problems and ease infections, and a gastrostomy—I cannot read this.

Senator HARKIN. That is all right. Take your time, just take your time. We are not in that big a hurry around here. Just take your time.

Mrs. WASIK. And a gastrostomy to enable him to receive nourishment directly by a tube into his abdomen. David has a number of medical problems, but he remains a loving and happy child, with a keen sense of humor. David likes television, particularly game shows and situation comedies. He likes country and western music and Elvis. David cannot speak, but lets us know what he wants and likes by smiling, laughing and stretching his legs.

After David left the hospital, we were told that he required nursing home care, and we placed him into the closest available nursing home that accepted children. It is about an hour and a half from our home.

Our statewide advocacy group, Michigan Protection and Advocacy Service, or P&A, as it is called, became concerned about the conditions at David's nursing home. In November 1985, P&A became aware that the nursing home was suspected of providing inferior care to the 133 multiply-impaired children who lived there. P&A staff visited the nursing home in order to investigate the allegations made.

During their first visit to the nursing home, staff observed widespread use of restraint devices throughout the facility. Many of the children's beds resembled cages and became known as "cage cribs" in that they had bars or plastic caps over the tops of standard cribs in which the children not only slept, but spent most of their waking hours when not at school.

Many of the children wore socks over each hand that had been securely taped to their wrists. Most children wore cloth restraints, tying them into wheelchairs.

The second floor where the children lived had an odor of urine and feces and was uncontrollably hot. Flies were observed crawling over furniture and food and around the children's faces. Many children were unable to move their arms in order to swat them away.

P&A staff conducted many monitoring visits within the first several weeks and filed a 12-page administrative complaint containing 85 allegations of violations to the Michigan Department of Public Health Code. In addition to the complaint action, P&A staff developed several other concurrent strategies. All staff committed to the frequent monitoring visits to the facility resulting in detailed observational reports. From these reports, a total of 11 public health complaints were filed on behalf of the children at this facility.

P&A staff met with other State departments in order to encourage the development of alternate programs to serve the children. As a result of these meetings, the Michigan Department of Mental Health began to develop an alternate plan for moving all of the children into either specialized foster care homes or intermediate transitional care units of approximately 20 to 30 children per unit. David became slated to move into a transitional unit.

Public Health's response to the nursing home situation was minimal, and when delays began to occur, the P&A strategy turned to ensuring the safety and well-being of the children until they were moved from the nursing home.

The health conditions of many children began to deteriorate, and deaths were feared. Bedsore ulcers developed frequently, and unexplained broken bones occurred with several children.

An independent medical assessment was done of each child, which found that at least 80 percent of the children suffered from malnutrition. By February of 1986, it seemed that the transitional units could open, but then a chicken pox epidemic swept the nursing home, extending the moving date indefinitely. With many children in dangerous medical condition, the chicken pox epidemic was determined extremely dangerous, and to complicate matters, many area hospitals would not admit the children because of the contagious disease factor.

We brought David home for three weeks so that he would not be subjected either to the disease or the disorganization of the nursing home. P&A exhausted the informal and administrative avenues for change and believed the remaining children were in imminent danger of harm and so went into circuit court to seek a writ of mandamus, ordering the Department of Public Health to enforce its statutory mandate and ensure a safe environment for the children while they remained in the nursing home.

Within one week, a stipulation was agreed to which ordered the changes necessary to assure the safety of the children. In March, David moved to a transitional unit, and on April 8, 1986, the last child left the nursing home.

Eighty of the children were placed into three transitional care units. The remaining children were placed into individual foster care homes or returned to their natural families. Most of the children have made substantial medical and personal growth gains during this interim time. Individual foster care homes have been the most successful placement alternative for the children, thus demonstrating that all children, even those with mild to severe medical conditions, are most successfully cared for in a home setting.

The children continue to gain new skills and are developing abilities long suppressed by years of neglect. Children who were restrained in wheelchairs or cage cribs are now learning to walk. Many of the children have been determined to have no mental retardation and are reversing the effects of lifelong institutionalization by learning to read, write, and attend to their own personal needs.

David left the transitional care unit and returned home two weeks ago. A nurse provided by the Department of Mental Health comes into our home each day to care for David while we are at work. We have been assured that this service will continue until our application for a Medicaid waiver is approved and in-home funding will begin through Medicaid.

While we still experience fears for the future should anything happen to the Medicaid waiver program or David's continued eligibility, we are thankful that our family is together once again.

David has made great progress since leaving the nursing home a year ago. He went from almost no school attendance at the nursing home because he was ill almost every day with infections and-or pneumonia to regular attendance after transferring to the transitional unit, and his health improved dramatically. The warm environment of the transitional unit and the tripled staffing ratio meant that David received the individualized attention and caring that he needed. As parents, we felt more at ease knowing that he was in the new environment.

While the transitional unit was an improvement over the nursing home, we still disagree with the physician services provided to David. We were not kept totally informed regarding some of the medical procedures performed and disagreed with others. Now that David is back home, he will be able to see the physicians and specialists of our choice, and we will again be on top of his medical care.

Throughout David's stay at the nursing home and the transitional unit, the Michigan Protection and Advocacy Service monitored services and quality of care that he received. As parents visiting the nursing home in order to pick David up for the weekend, we were not aware of the conditions that existed on a day-to-day basis. If P&A had not intervened and brought about the closing of the nursing facility, many children would still be contained in that environment.

Protection and Advocacy has been available to answer our questions as they arise and to assist us in utilizing administrative complaint processes. Since David is back home, we know that we can call on the P&A to assist us with any issues that may come up. We were told by staff at both the nursing home and transitional unit that following a visit home, David would remain depressed, withdrawn, and sleep for days after returning to the facility. Now he smiles spontaneously and frequently and is excited to be part of the daily family circle. David does not want to go to sleep during the day; he does not want to miss anything.

Thank you.

[The prepared statement of Mrs. Wasik and responses of questions submitted by Senator Harkin follow:]

TESTIMONY
ON THE
DEVELOPMENTAL DISABILITIES AND BILL OF RIGHTS ACT

SUBMITTED BY

LYNN WASIK
HIGHLAND, MICHIGAN

ACCOMPANIED BY ROBYN FRIEDMAN
MICHIGAN PROTECTION AND ADVOCACY SERVICE

WEDNESDAY, APRIL 8, 1987

SENATE COMMITTEE LABOR AND HUMAN RESOURCES
SUBCOMMITTEE ON THE HANDICAPPED

Mr. Chairman, I want to thank you for the opportunity to testify before the Members of this Subcommittee. It is a great honor to be here in Washington, and to be asked to provide such valuable information to you and the Subcommittee. I am Lynn Wasik of Highland, Michigan, here today representing my son David, the Michigan Protection and Advocacy Service and the fifty-five (55) other Protection and Advocacy Systems throughout this country.

David Wasik is fifteen years old. He has had developmental disabilities since birth. David has been diagnosed as having cerebral palsy, affecting his ability to use his arms and legs; mental retardation, the extent of which has been difficult to determine since David cannot communicate by traditional means; and a seizure disorder that requires medication. Until David was thirteen years old, he lived at home with my husband, Dennis, his younger brother, Steven, and myself. At that time, a series of respiratory problems, an inability to continue to eat food orally, and weight loss forced David into the hospital. He received a tracheotomy to relieve breathing problems and ease infections, and a gastrostomy to enable him to receive nourishment directly by tube into his abdomen. David has a number of medical problems, but he remains a loving and happy child with a keen sense of humor. David likes television, particularly game shows and situation comedies. He likes country-western music and Elvis Presley, and he loves to be held and talked with. David lets us know what he wants and likes by smiling, laughing and enthusiastically stretching his legs and toes far out.

After David left the hospital, we were told that he would need to be cared for in a nursing home. We trusted this advice from the doctors in the hospital and placed him into the closest available nursing home accepting children, about an hour and a half from home, in April, 1985. We brought him home as many weekends as was possible even though his health continued to remain very poor with frequent upper respiratory infections and pneumonia. We were unhappy and constantly worried and stressed about his health as well as his living environment.

Our state-wide advocacy group, Michigan Protection and Advocacy Service (MPAS) became concerned about the conditions at David's nursing home. In November, 1985, the Michigan Protection & Advocacy Service (P&A), became aware of this suburban Detroit nursing home which provided care to 133 multiply impaired children, through a phone call received from a teacher involved in the school program provided to the children. She was concerned about the appearance of the children when arriving at school in that many had not been assisted with personal care needs. She noted that a number of children appeared to have received infrequent bathing, wore ill-fitting or mis-matched clothing, seemed listless during the day, looked thin or undernourished, used wheelchairs and other equipment needing major repairs, and came to school in seasonally inappropriate clothing.

P&A staff visited the nursing home in order to investigate the allegations made. During their first visit to the nursing home, staff observed a widespread use of restraint devices throughout the facility. Many of the children's beds resembled cages and became know as "cage-cribs" in that they had bars or plastic caps over the tops of standard cribs in which the children not only slept but spent most of their waking hours, when not at school. Many of the children wore socks over each hand that had been securely taped to their wrists. Most children wore cloth restraints tying them into wheelchairs. A mealtime was observed in which all food was prepared ground or pureed. Those children who could feed themselves were pushed in wheelchairs up to a window ledge where plates were balanced. A foster grandparent remarked that some of the children were not fed dinner until 8:00 p.m. because of the severe understaffing on the unit. During this first visit the P & A observed only eight direct care aides and one registered nurse to care for the 133 children. During the meal, children were observed lying flat on floor mats while spoons of pureed food were rapidly pushed into their mouths. P&A staff observed two children regurgitating following the meal as they remained on the floor. Aides busy attending other children did not come to their assistance until P&A staff insisted that they do so.

The second floor, where the children lived, had a pervasive odor of urine and feces and was uncomfortably hot. Flies were observed crawling over furniture and food and around the children's faces moving in and out of their noses and mouths. Many children were unable to move their arms in order to swat them away.

P&A staff conducted four monitoring visits within the first several weeks and filed a 12 page administrative complaint containing 85 allegations of violations to the Michigan Department of Public Health Code. Public Health has the statutory responsibility for investigating and enforcing nursing home regulations and the Nursing Home Patient's Bill of Rights Act. The complaint covered the five major areas of: improper use of restraints, environmental concerns, abuse/neglect, quality of care issues, and staffing ratios.

It became almost immediately apparent that the Public Health response to this complaint and the situation in general would not be swift or aggressive, as had been anticipated. Therefore, in addition to the complaint action P&A staff developed several other concurrent strategies. All Southeast Michigan staff committed to frequent monitoring visits to the facility resulting in detailed observational reports. From these reports a total of 11 Public Health Complaints were filed on behalf of children at this facility.

P&A staff began a series of meetings with the Michigan Department of Mental Health in order to encourage their involvement and the development of alternative programs to serve the children. P&A staff met with the nursing home corporation in order to directly advise them of concerns and request changes in living conditions for the children. Staff also began a series of meetings with Public Health in order to facilitate the complaint investigation process and to request that they initiate stepped-up monitoring and enforcement as per their statutory power.

Despite timelines, it took two and one-half months for the Public Health Department to respond to the initial complaint. Of the 85 allegations cited in the complaint, Public Health found only 9 violations of regulations. Upon review of their findings, Public Health had not investigated 43 of the P&A allegations. Those found to be investigated but not substantiated were primarily the result of the investigator not personally observing the alleged violation. As a result of he 9 substantiated complaint allegations, Public Health levied a fine totaling $800.00 against the nursing home corporation. Of this $800.00, three of the children were to receive $100.00 each for the pain and suffering endured.

Of the other 10 Public Health complaints filed by P&A staff on behalf of individual children, only one complaint was substantiated by Public Health. Three of the non-substantiated complaints were filed on behalf of children who had died either at the nursing home or shortly after being taken to a hospital. One child died as a result of his head becoming stuck between the bars of his crib. Another was found lying comatose in a beanbag chair, on the floor, and died the following day at a hospital as a result of aspiration pneumonia. A third child who had been on an apnea monitor at the nursing home was transferred to a hospital with labored breathing without the monitor or medical records. The child was never placed on a monitor at the hospital and child died alone in his room several days later.

Protection and Advocacy meetings with the Michigan Department of Mental Health (DMH) progressed more favorably. DMH began to develop an alternative plan for moving all of the children into either specialized foster care homes or intermediate transitional care units of approximately 20 to 30 children per unit. These transitional units would remain in place until the children could be placed into individual foster care homes or back with their natural families.

Despite the Department of Mental Health's efforts to put into place the necessary services, delays began to arise. P&A strategy turned to ensuring the safety and well being of the children until their move from the nursing home. Concern began to rise as the health conditions of many of the children began to deteriorate and further deaths were feared. Decubitus ulcers developed frequently sometimes creating a large wound that went nearly to bone depth. An independent medical assessment was done of each child which found that at least 80% of the children suffered from malnutrition. By February, it seemed that the transitional units could open, and then a chicken pox epidemic swept the nursing home extending the moving date indefinitely.

Public Health did not seem capable of ensuring a safe environment for the children. DMH was not able to move the children from this environment until a chicken pox free incubation period occurred as per Public Health's contagious disease standards. The nursing home refused to provide adequate staffing or recognize the need to improve the standard of care provided to the children. P&A staff met with the state Attorney General's office in an effort to elicit their intervention by requesting Public Health to enforce the statutory standards of care and/or to press charges against the nursing home for abuse. The Attorney General's office declined involvement on these issues. Another child died at the nursing home, proximate cause of death undetermined.

DMH committed a registered nurse to daily monitoring at the nursing home. Conditions did not improve and the children continued to remain at high risk. Physician services to the nursing home became unreliable as the contract physician resigned in a letter criticizing the quality of care provided to the children. Nurses reported a lack of basic equipment such as stethoscopes, a pediatric blood pressure cuff, and thermometers. Most of the children were determined to have feeding problems due to decreased alertness, spasticity and swallowing problems which resulted in malutrition. The children required careful physical and occupational therapy evaluations ~~in~~ order to address this issue, and staff required training on feeding techniqes in order to reverse the malnutrition and resulting effects. These issues also affected the children's fluid intake and many were dehydrated which resulted in frequent instances of aspiration pneumonia. With many children in precarious medical conditions, the chicken pox epidemic was deemed extremely dangerous, and to complicate matters, many area hospitals would not admit the children because of the contagious disease factor.

After exhausting the informal and administrative avenues for relief, and believing the children to be in imminent danger of harm, P&A staff went into circuit court to seek a Writ of Mandamus ordering the Michigan Department of Public Health to exercise its authority by enforcing the statutory and regulatory provision available in order to assure a safe environment for the children while they remained in the nursing home. Within one week a stipulation was agreed to which ordered: that a physician would be provided to monitor and evaluate the ongoing medical conditions of the children at the nursing home; that Public Health would assure necessary nursing staff to child ratios, including the maintaining of documentation regarding each child's food and fluid intake in an accurate and current manner; that Public Health would agree to immediately arrange for a registered dietician to assess the dietary needs of the children on an individual basis, a social worker for consultation wih parents or guardians, and a sanitation inspection; that all necessary medical equipment would be available; and that nursing home staff would receive immediate training in appropriate feeding techniques. A timetable for transferring the children out of the nursing home was also established.

On April 8, 1986, the last child left the nursing home. 80 of the children were placed into three transitional care units. The remaining children were placed into individual foster care homes or returned to their natural families. Most of the children have made substantial medical and personal growth gains during this interim period. Individual foster care homes have been the most successful placement environment for the children thus demonstrating that all children, even those with mild to severe medical conditions are most successfully cared for in small individualized home settings. Many of the children who returned to their natural homes continue to receive in-home support services from DMH. To date, two of three transitional units remain open although one is slated to close within the next 30 days, as foster placement development continues to progress at an even pace. Michigan Protection and Advocacy Service remains involved with the children through monitoring the services provided at the transitional care units and through the ongoing administrative processes related to the previously filed Public Health complaints.

The children continue to gain new skills and are developing abilities long repressed by years of neglect. Children who were restrained in wheelchairs or cage-cribs are learning to walk. Many of the children have been determined to have no mental retardation and are reversing the effects of life-long institutionalization by learning to read, write, and attend to their own personal care.

David left the transitional care unit, and returned home two weeks ago. A nurse, provided by the Department of Mental Health, comes into our home each day to care for David while we are at work. We have been assured that this service will continue until our application for a Medicaid waiver is approved and inhome funding will begin through Medicaid. While we still experience fears for the future should anything happen to the Medicaid waiver program or David's continued eligiblity, we are thankful that our family is together once again.

The progress that David has made since leaving the nursing home, a year ago, is immeasurable. We were informed that David could not leave the nursing home in order to attend school but that he could participate in the in-house school program established to provide homebound services. However, David rarely attended even this program as we were informed that he was ill almost every day wiht upper respiratory infections and/or pneumonia. This meant that he spent the greater part of every day in bed, sharing a connecting bedroom with nine other children. When David transferred to the transitional unit, he began regular attendance at the in-house school program and his health improved dramatically. During the entire past year, he has had only two instances of pneumonia present as opposed to a nearly constant state of infection and fever experienced the preceding year at the nursing home. His improved health has also meant gains in strength, endurance and weight. In the past year, he has gone from wearing size five clothing to a size ten or twelve.

The warm environment of the transitional unit, and tripled staffing ratio meant that David received from the direct care staff, the individualized attention and caring that he needed. As parents, we felt more at ease knowing that he was in the new environment. While the transitional unit was a vast improvement over the nursing home, we still disagreed with the physician services provided to the children on the unit. We were not kept totally informed regarding some of the medical procedures performed, and disagreed with others. Now that David is back home, he will be able to see the physicians and specialists of our choice and we will again be on top of his medical care.

Throughout David's stay at the nursing home, and the transitional unit, the Michigan Protection and Advocacy Service monitored the services and quality of care that he received. As parents visiting the nursing home in order to pick David up for the weekends, we were not aware of the truly terrible condition existing on a day to day basis. If the P&A had not intervened and brought about the closing of the nursing facility, many children would still be contained in that environment. I wonder how many more children would have died. I wonder where David would be today.

I was also relieved to know that the Michigan Protection and Advocacy Service followed the children to the various transitional units and continued to monitor the care and services provided. P&A staff were available to answer our questions as they arose and to assist us in utilizing the administrative complaint process when we disagreed with a physician's ordered procedure. Since David is back at home, we know that we can call on the P&A to assist us with any issues that may arise. We know that David will return to his local school program and that the P&A can assist us in obtaining the specialized transportation services he will need. The P&A can also assist us if we run into any problems with the Medicaid waiver process, or in identifying community or in-home services.

We were told by staff at the nursing home and transitional unit that following a visit home David would remain depressed, withdrawn and sleep for days after returning to the facility. Now, he smiles spontaneously and frequently and is excited to be a part of the daily family circle. He is definitely the only member not to get tired of the dog barking. David does not want to go to sleep during the day. He does not want to miss anything!

This year 1987 marks the 10th anniversary of the Protection and Advocacy (P&A) System for People with Developmental Disabilities. This anniversary coincides with the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. The P&A System has grown from its early years, both in funding levels, authority, and experience. The P&A System has grown from an initial funding of $2.5 million in FY 1976 to $15.5 million in FY 1987; however, the broad mandate developed in the legislation in 1975 has not yet been fully realized, and the service needs of persons with developmental disabilities still require expansion of aggressive advocacy services.

In fiscal year 1986, Protection and Advocacy Systems provided direct services to 50,000 clients. In addition, thousands of persons benefitted from systemic actions initiated by the P&A Systems. These figures do not include the thousands of persons with disabilities who received information and referral services from the P&A Systems as well.

An indication of the success of the Protection and Advocacy System in promoting the independence of persons with developmental disabilities is the fact that over 80 percent of the cases in which Systems intervened on behalf of the client in fiscal year 1986 were resolved satisfactorily. In addition to providing direct assistance to their clients with developmental disabilities, the P&A agencies are constantly involved in activities intended to change systems at the State and local levels and resulting in a larger number of persons with disabilities being served.

With the passage of the Protection and Advocacy for Mentally Ill Individuals Act of 1986, Congress reaffirmed its commitment to the Protection and Advocacy model by extending these services to individuals labeled mentally ill throughout the country. The Act provided $10 million for each of 3 years to protect and advocate for persons who are labeled mentally ill and reside in facilities providing care and treatment.

The problems of persons with developmental disabilities inappropriately placed in nursing homes is one of a number of critical issues facing the P&A Systems. Others include:

1. minority outreach
2. persons who have developmental disabilities who are within the criminal justice system
3. children in least restrictive educational settings

The P&A Systems, however, have been forced to set priorities for services, and many persons have been placed on waiting lists, often the very problem, the client wished the P&A to address in the service system.

The P&A System has demonstrated its effectiveness in its first decade of operation, and is anxious to reach its full potential in the second decade but will do so only with adequate resources with which to address all clients in need.

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United States Senate
COMMITTEE ON LABOR AND
HUMAN RESOURCES
WASHINGTON, DC 20510-6300

April 10, 1987

Lynn Wasik
106 8th South Park Street
Highland, Michigan 48031

Dear Lynn,

Thank you for testifying before the Subcommittee on the Handicapped regarding the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. It was a pleasure to have you as a witness. Your testimony was eye-opening and helpful.

There are a number of questions to which my colleagues on the Subcommittee and I would appreciate your response. Please provide me with your comments on the following:

1. What do you feel are the most important issues that the Congress should address in its reauthorization of the Developmental Disabilities Act?

2. Please comment on the Administration's proposal for a new priority of Family Support Services and how it might be beneficial to you.

3. How do you feel Congress can best address the needs of individuals with developmental disabilities who are becoming older adults?

I look forward to receiving your responses to these questions and thank you in advance for your continued assistance to us as we consider the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. Please provide me with your written comments by April 23, 1987 when the record of the hearing will be closed.

Sincerely,

Tom Harkin

Tom Harkin
Chairman, Subcommittee
on the Handicapped

cc:Curt Decker
TH/kb

April 23, 1987

The Honorable Tom Harkin
Chairman, Subcommittee
on the Handicapped
Hart Senate Office building
Room 317
Washington, DC 20510-1502

Dear Senator Harkin:

On behalf of myself and my family, I wish to express my sincere appreciation for the opportunity to speak before your committee on April 8, 1987. I also appreciate the kindness extended to me by all the Subcommittee members.

In response to your questions I wish to respond as follows:

1. I believe the Developmental Disabilities Act must be extended and expanded in order to continue to help families such as mine. Certainly, increased resources for all the programs, funded under the act are necessary. I also believe that all persons with developmental disabilities should receive assistance regardless of the disability category in which they fall. I also strongly urge that the act strengthen services to families so our children can live in their own houses or in homes which are in their community.

2. As a family with a child with a severe disability, community and home support services are critical to our maintaining David in our home. We especially need respite services for David to relieve my husband and I and our family members from time to time. David's medical problems require extensive nursing care and we are constantly nervous that those services would be reduced which would force us to put him back into another facility.

3. We are worried about David's future as he grows older. David needs a home in the community especially if we become unable to care for him. David and other children like him need help to transition to adult services as they end their relationship with the education system. Rehabilitation services and work opportunities should be available to them. I am told that unlike P.L. 94-142, vocational rehabilitation services are not guaranteed for everyone. How will David get these services?

Senator, families like mine are depending on your leadership to help us. Thank you again for your concern.

Very truly yours,

Lynn Wasik

Lynn Wasik
Highland, Michigan

Senator HARKIN. Thank you very much, Mrs. Wasik, for that testimony. If I had not pre-read this, and I did not know about what you were talking about, I would assume that you were talking about something that happened in the last century; it at least sounds like that.

Mrs. WASIK. No. It happened in the last two years.

Senator HARKIN. Rather than moving to questions now, what I would like to do is go to all of the panel members, and then we will come back and get you involved all together.

Thank you very much for coming this great distance and testifying.

Mrs. Everitt, welcome to the Committee, and as with all the rest, your statement will be made a part of the record, and please summarize.

Mrs. EVERITT. Thank you.

My name is Dee Everitt. I am from Lincoln, Nebraska, and I guess if I have any credentials, it is that I am the immediate past President of the Association for Retarded Citizens of the United States, and I also presently chair their Governmental Affairs Committee.

I guess more importantly, I am here as Christine Everitt's mother. My daughter Christine is 34 years old. She has cerebral palsy, mental retardation, and a very serious seizure disorder. Chris takes a number of medications, 24 pills a day to be exact, which cause a lot of problems in the area of toxicity.

She suffers from a seizure disorder which is known as status epilepsy, so in other words, from time to time she is hospitalized; she has numerous seizures, like every two minutes, for two or three weeks at a time. This plays havoc with her body and her psyche, obviously, and always we just barely make it, but we always have.

We have four grown children; Chris is our second. Even though I live in a State that has a reputation for having developed a network of community-based services as early as in the Sixties, it seems that we have not made a great deal of progress in serving the more severely handicapped individuals.

Chris attends a day program which is called, loosely, a workshop. However, this program provides little more than sporadic, inappropriate contract work, a great deal of down time, and a great deal of boredom. Chris is bored to tears. Consequently, she sleeps a lot and does not want to attend.

Last year, Chrissie earned all year $249. We paid $300 to get her there in a van, so you can see it is a losing proposition. There are 80 people who attend the program. It lacks in creativity, and it appears for her and many of her friends to be a dead end.

This program does nothing for her self-image and does not give her a lot to look forward to. Now, obviously, my husband and I are not getting any younger. Chris should be moving out of our home. We know that. We do much better in Nebraska in the area of residential services. However, getting an appropriate residential service seems to be the problem. Recently we were given an opportunity to place her in a group home, which was not appropriate. The other four people were aggressive, assaultive people, and because of Chrissie's physical disabilities, she is very vulnerable.

The services should be provided, as we all say they are, but they are not, necessarily on individual need and not just where there is an opening.

I want Chris to have a productive life, and the hope of her being able to function on a work station with supervision gets more dim as time passes for Chris. She is not being trained to work. She is being allowed to sit and do nothing.

As a family, it is a full-time job to keep her image and her self-worth at an adequate level. She has three brothers who are all very caring and extremely interested in what happens to her. However, as I said, since we are reaching retirement age, the worry of what will happen to Chris when we are gone is much more immediate.

I do not expect Developmental Disability Councils to deliver direct services. I realize that is not their role. However, I do believe that the Councils in the various States should be making sure in their planning process that State agencies funded with public moneys address the reasons for waiting lists, which are predominant in every State, and how the State can address that problem.

The DD Councils should be making an adequate assessment of the needs in each State, the gaps in services for individuals, and why this is happening. They should then exercise their role and responsibility to be a true change agent and see that systems are working right.

Chris and all other persons with DD cannot wait forever to see that something happens to make their lives more productive. Maintenance in programs are not what I had in mind for her.

I thank you for allowing me to appear before you at this hearing. I support the program, and I hope that it can be strengthened to function in a way that will help all persons with disabilities. DD Councils should make services stronger, help in the planning of those services so that people with DD may be better-equipped to live in the community with dignity and independence.

Thank you.

[Responses of Mrs. Everitt to questions submitted by Senator Harkin follow:]

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United States Senate
COMMITTEE ON LABOR AND
HUMAN RESOURCES
WASHINGTON, DC 20510-6300

April 10, 1987

Delores Everitt
4325 Meredith
Lincoln, NE 68506

Dear Dee,

Thank you for testifying before the Subcommittee on the Handicapped regarding the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. Your testimony is extremely important in that it raises yet another challenge to our service system -- the needs of the adult and aging disabled in our nation.

There are a number of questions to which my colleagues on the Subcommittee and I would appreciate your response. Please provide me with your comments on the following:

1. How do you feel Congress can best address the needs of individuals with developmental disabilities who are becoming older adults?

2. What do you feel are the most inportant issues that the Congress should address in its reauthorization of the Developmental Disabilities Act?

3. Please comment on the Administration's proposal for a new priority of Family Support Services and how it might be beneficial to you.

I look forward to receiving your responses to these questions and thank you in advance for your continued assistance to us as we consider the reauthorization of the Deveolopmental Disabilities Assistance and Bill of Rights Act. Please provide me with your written comments by April 23, 1987 when the record of the hearing will be closed.

Sincerely,

Tom Harkin

Tom Harkin
Chairman, Subcommittee
on the Handicapped

cc: Paul Marchand
TH/kb

Senator Tom Harkin
Chair, Subcommittee on the Handicapped
Washington, D.C. 20510-6300

Dear Sen. Harkin:

I enjoyed participating on the panel at the recent hearing on Developmental Disabilities Act. I will try to answer the questions you have submitted to me.

1. Congress must find a stable funding source from the federal level so that older adults with mental retardation and other disabilities can live in dignty within the community and maintain the same level of life style that they have had in their natural homes. In my daughters day program, there are many many individuals who live at home with parents who are over 60. Many of them attend this program because there is nothing better and the program in inappropriate and boring. They first of all need a day program that is designed to meet their needs. They also need appropriate places to live in the event that these older parents become sick or die. Many older persons with disabilities are placed in residential settings that is there because there is an opening, not because it suits their needs. These programmtic issues will probably have to be dealt with at a local level, however the Congress should seriously look at the way medicaid funding, for instance, is being spent at the present time. We who have not chosen to institutionalize our sons and daughter feel that medicaid should be reworked so that these eligible people can use these funds in the community and not have to enter a larger institution to take advantage of medicaid. We would like the same kind of secure funding source in the community as medicaid now gives to individuals and parents of those in institutions. It would give our families a great more security and peace of mind, especially in the area of residential services, in the community.

In conclusion, make sure all laws which affect older adults are clear in establishing eligibility for that portion of the population which is DD. In particular the Older Americans Act should also be amended where appropriate, to insure eligibility. We again recommend those aging related provisions contained in CCDD Testimony in regards to the DD Act.

2. Congress should make sure that every state is using a portion of their DD monies to do appropriate systems planning, making sure that state agencies that are responsible and designated to provide services, are doing an appropriate job and serving everyone that is eligible. The waiting list issue is becoming a large one in most states. DD Councils should be taking a long hard look at these waiting lists, whether they are accurate, why they exist and why the appropriate agencie is not addressing the needs. It would be helpful if the councils would help agencies develop programs of supported employment for the severely handicapped. They should be promoting this mode of work and support and train staff to work with these individuals and to also promote and find businesses that would hire individuals under these conditions.

page 2

In conclusion, we recommend to you the full recommendations of CCDD are accepted.

3. Family support should be a priority for every human service agency. We need to get off the track that says everyone should be taken from the natural home and put in foster care, group homes, or made state wards. The assumptions from most professionals is that DD persons would always do better somewhere else. The available dollars would go much farther if we begin supporting families and serving individuals in there natural home, especially when families want to do this. For 35 years we have had Kris at home. She loves her family and we all love her very much. She needs to be loved and accepted. However, many families simply cannot manage. Counseling to families, as a family should be offered so that behaviors which can really test a family, can be addressed by the family. Just removing an individual from the home Does not corrects all things. Often they then feel they have done something wrong and are being punished. Nebrask'a Dept. of Social Services is now trying to actively support families and provide the needed services. It is difficult to get staff, case managers and administrators to change their ways if they have been doing it one way for years. They are finding it saves money, addresses needs that usually become greater if you move people out, and makes professionals more accountable.

Our family could use better and more accessible respite workers, help in bathing, and lifting our daughter, better care at home and relief when Kris has a bout with status epilepsy amd seizures non stop for days, and devices to make it easier to care for her at home. We have always managed, one way or the other, sometimes better than others, but it has occurred to us many time that the system in Nebraska subtly encourages people to be moved out. Then you get a great array of services, but if you keep your individual at home you are, in a sense, punished. Now that my husband is nearing retirement, we would like to keep Kris at home as long as we can. However money will become a bigger problem on retirement money and a fixed income. We have three sons who we have managed to give college educations to despite the fact I have never worked. Short term care, out of the home would also be helpful. It would ease individuals into a life away from home so that it would not be so traumatic when death or illness makes it suddenly necessary. Short term, out of home care, could give everyone some much needed rest.

Given the existing priorities of "Alternative Community Arrangement Services," which appears to accomodate what the administration is trying to accomplish, we however suggest that the term include counseling for families and individuals.

Thank you for asking for my responses. Since I am doing this on short notice the comments are not as articulate as I might like them to be but I am sure the intent of my thoughts are clear.

Sincerely
Dee Everitt
Dee Everitt
4325 Meredeth
Lincoln, Ne. 68506

cc P. Marchand

Senator **Harkin**. Thank you, Dolores, for that testimony. I am going to have some questions and just jotted some things down here. But thank you for coming this great distance—Lincoln, Nebraska, right?

Mrs. **Everitt**. Yes.

Senator **Harkin**. Now, we will turn to Todd Kilroy for your testimony, and again, without objection it will be made a part of the record.

Please proceed.

Mr. **Kilroy**. (Translated through communication board.) Good afternoon, Senators. My name is Raymond Kilroy. I live in Unionville, Connecticut, and I am very pleased to be invited to testify on the reauthorization of the Developmental Disabilities Act.

I brought George Ducharme with me in the event you do not understand me or my communication board. George is from North Granby, Connecticut.

I lived with my family until I was 20 years old, when I was placed at New Britain Memorial Hospital, an institution for people with disabilities. At the time,this was the only option for families with children with disabilities.

I am now 50 years old. I have spent most of my life in an institution. I have recently moved from New Britain Memorial Hospital to a new facility called New Horizons Village. Many people consider New Horizons Village an institution, too.

Mr. **Ducharme**. If I may, Senator, Raymond realized it was impractical to give his whole testimony with this machine, so he asked me if I might read his written testimony for him.

Senator **Harkin**. Only if after the hearing is over, you show me how that thing operates.

Mr. **Ducharme**. Sure. He told me if he could teach me, he would teach anyone.

Senator **Harkin**. I am a technological nut, and I have never seen one of those. I would like to see how that operates. So if you have some time afterward, if you do not have to run off, that is pretty interesting.

Mr. **Ducharme**. Thank you, Senator.

Continuing on, "I am, however, planning to move from New Horizons Village to my own apartment or housing cooperative."

"I am sure that many of the speakers you have listened to today have told you about all the accomplishments of the Developmental Disabilities Program. I, too, have benefitted from changes in Connecticut's system of services for persons with developmental disabilities generated by the DD Council."

"While I was a DD Council member and chaired one of its major committees, I helped move Connecticut into supported and integrated employment and the use of rehabilitation engineering."

"I took advantage of this movement and used rehabilitation engineering to get a part-time job using a computer for data processing at Connecticut Blue Cross-Blue Shield. It is the first job I have ever had."

"While I am proud I have been part of getting people with developmental disabilities into supported and integrated employment in Connecticut who used to be kept busy and segregated in sheltered workshops, earning little or no income, I am more excited about where the DD Council and I are going. We are trying to change the way the public and private system thinks and acts toward people with developmental disabilities."

"We are moving away from emphasizing my needs toward building upon my capacities. We are moving away from providing services to me from some facility toward building bridges with me to community and neighborhood associations. We are moving away from serving me and other people with disabilities toward empowering us and families to acquire the support we want. We are moving away from focusing on my deficits to focusing on my competence. We are moving away from specialized disability organizations to adapting generic community organizations so that we can develop and sustain relationships with people who will depend upon people like me and upon whom people like me can depend."

"I am very pleased that I am one of six individuals and families within whom the DD Council is demonstrating personal futures planning and bridge-building to neighborhood associations over the next three years."

If I may, I would like to introduce Gretchen Bilow, who is going to be helping us with some of the visuals that are prepared by my colleague Beth Mount. She listens to Raymond and Raymond's friends describe where he is, who the people he knows are, and what he would like to have as his image of the future.

Senator **Weicker**. George, I have just been asked to come to the Floor by the Minority Leader Senator Dole, to manage the homeless bill which is on the Floor. I have got to do that immediately. But I did not want to leave without expressing my pride in Todd, indeed in you, and all those who are working so hard in our State. And your testimony, believe me, is eloquent indeed, as is the testimony of others here.

You give us, really, the inspiration to carry the fight to the Floor and other places. But I did want you to see me jump out of my seat and figure, "Well, he is bored." I am not bored. To me, this is what makes life worthwhile being a United States Senator—all of you taking the time to come here and relate your stories.

But I thought you would also agree that the homeless bill is something you would want me to go ahead and respond to, since the call has gone out on that.

Mr. **Ducharme**. Absolutely. Thank you very much.

Senator **Weicker**. Thank you, Mr. Chairman.

Senator **Harkin**. Thank you, Senator Weicker.

Go ahead, Mr. Ducharme.

Mr. **Ducharme**. "Personal futures planning enables me and my friends to plan together to establish a common direction and share strategies so that I can obtain a valued role in my community."

"Bridge-building assists me in building bonds, relationships and friendships with people in generic neighborhood associations in my community. My personal futures plan is on the several charts that Gretchen is holding. We chose three; there are numerous more in the back."

"It has been reduce to eight and a half by eleven and a half paper in my written testimony, which I believe you have."

"With George, I would like to share with you where I am going and how the DD Council is going to help me get there."

These are Todd's images for his future.

Senator HARKIN. And Todd, you put those together, right? These are based on your concepts of your future planning.

Mr. KILROY. Yes.

Mr. DUCHARME. These are generated in a personal interview with Raymond and some friends that Beth drew out for him.

"I want to get off welfare. To get off welfare, I need a full-time job that pays benefits. To live independently, I need support from personal care attendants. I needed adapted housing. I want to live near my job, own my own place, and have my own room. I am interested in cooperative housing."

"I need adaptation so I can communicate more easily. In my town, I want to be involved in my church and take adult education courses. I want to learn more about music and go to concerns and outdoor trips. Maybe I will even get married."

"What is most significant about my plan is that I have determined my own needs, and I designed my own future for myself, my family, my neighborhood, and those institutions that have an impact on my life. My future is not controlled by agencies and professionals. While specialized disability organizations are a part of my plan, most of the help I am getting is coming from family, friends and neighbors. They are not paid staff."

"Full participation in the community is more important to me than entrance into an agency's programs."

"I ask you to reauthorize the Developmental Disabilities Act and to expand its ability to empower individuals and families to control our own futures. I ask you to move the developmental disabilities program way from providing service toward empowering me and families to acquire the support we want. I ask you to move the developmental disabilities program away from enhancing specialized disability organizations to adapting generic neighborhood associations."

Todd has written a final paragraph, which he would like me to deliver.

"One of my hopes is that the work of positive futures planning will be added to all the independent living centers. As I said, I lived in an institution for 30 years. Even though I always wanted to move out, when that time came, it was quite traumatic. If the elements of futures planning could be incorporated with the work being done at the independent living centers, I think it would be an important advancement."

"Thank you very much."

[The prepared statement of Mr. Kilroy and responses to questions submitted by Senator Harkin follow:]

TESTIMONY BEFORE THE UNITED STATES SENATE SUBCOMMITTEE ON THE HANDICAPPED

BY RAYMOND KILROY, 57 BLISS MEMORIAL DRIVE, UNIONVILLE, CONNECTICUT

APRIL 8, 1987

Good afternoon, Senators. My name is Raymond Kilroy but most people call me Todd. I live in Unionville, Connecticut, and I am very pleased to be invited to testify on the reauthorization of the Developmental Disabilities Act. I brought George Ducharme with me in the event you do not understand me or my communication board. George is from North Granby, Connecticut.

My disability is cerebral palsy and my family is one of the founders of the United Cerebral Palsy Associations in Connecticut. At the time that I was born the only option for families with children with disabilities was placement in an institution. I am not mentally retarded so I was lucky not to be placed in a state institution for people with mental retardation. Instead, I lived at New Britain Memorial Hospital. I was placed there when I was 20. I have since spent most of my life in an institution. I have recently moved from New Britain Memorial Hospital to a new congregate living facility called New Horizons Village. I am, however, planning to move from New Horizons Village to be independent.

In May of 1979 I became a member of the Connecticut Developmental Disabilities Council and my term just ended on March 17th of this year. I co-chaired the Developmental Disabilities Council's Systems Review and Development Committee during 1985 and 1986 and I served on the Council's Executive Committee.

Much of my life changed while I was a DD Council member. With the help of the Division of Rehabilitation Services, I was able to complete college at Central Connecticut State University. I then got myself a Masters in Business Administration at the University of Hartford. At about the same time, the DD Council was changing the way people with disabilities, particularly people with severe and multiple disabilities, were being employed. Instead of sheltered workshops, the DD Council was pioneering supported employment in real jobs for real wages and integrated in real business and industry. In addition, the DD Council was experimenting with rehabilitation engineering to demonstrate that any job can be adapted to fit anyone's ability.

The DD Council flatters me by saying I am a success model for rehabilitation engineering and supported employment. I use an electronic communication board and I work part-time doing data processing at Connecticut Blue Cross/Blue Shield. A rehabilitation engineer adapted my computer and taught me how to use it.

I am very excited about how much change in employment the DD Council has generated. Connecticut now has in place over $3.7 million for marketing supported and integrated employment with business and industry, to provide technical assistance to convert sheltered workshops to supported and integrated employment, to establish supported and integrated employment projects and to facilitate the transitioning from Special Education into employment. We have over $18 million in state agency budget options to begin July 1, 1987 to expand these initiatives, to create a corporate job bank and to assist people to work and live independently. To date, there are 554 people with developmental disabilities in supported and integrated employment programs, working an average of 27 hours per week, 5 days per week, earning an average of $536 per quarter. These are people with severe and multiple disabilities who used to be kept busy and segregated in so-called sheltered workshops earning little or no income.

With the commitment from our Governor to continue to support economic self-sufficiency for people with disabilities the DD Council's role is changing. I am now more excited about where the DD Council is going than what we have done.

The Connecticut DD Council is trying to change the way the public and private system thinks and acts toward people with developmental disabilities. The DD Council is moving away from emphasizing my needs toward building upon my capacities. It is moving away from providing services to me from some facility toward building bridges with me to community and neighborhood associations. The Council is moving away from serving me and other people with the disabilities toward empowering us, and families, to acquire the support I want. It is moving away from focusing on my deficits to focusing on my competence. It is moving away from specialized disability organizations toward adapting generic community organizations so that I can develop and sustain relationships with people who will depend on me and upon whom I can depend.

I am very pleased that I am one of six individuals and families with whom the DD Council is demonstrating personal futures planning and bridge-building to neighborhood associations over the next three years. Beth Mount, from Graphic Futures, Incorporated, is my personal futures planner and George Ducharme is my bridge-builder.

My personal futures plan is on several charts 4' high and 3' wide and it has been reduced to 8-1/2" x 11-1/2" paper enclosed.

First, you will see this is not your typical Individual Program Plan. I am not aware of any Individual Education Plan, Individual Habilitation Plan, Individual Work Rehabilitation Plan, or Overall Plan of Care that allows for pictures, but the pictures are very important to me to envision who is important to me now, who do I need to get to know to help me to where I want to go, where I am now and where I want to go. I understand pictures better than I understand jargon.

Second, this is my plan. It was not planned for me by agencies and professionals. I have stated my preferences. I control my future.

Third, you will note that generic community programs are far more important to me than specialized disability organizations. Specialized disability organizations are a part of my plan but I determine what support I want from them.

Fourth, my plan doesn't list my deficits. My plan lists my competencies and employs them to realize my future.

Fifth, my plan is designed to help me participate fully in my community and neighborhood rather than to enter an agency's program.

Finally, the people who are helping me implement my plan are, generally, not professionals in the disability field. They are my family, friends and neighbors. They are not paid staff.

The kind of planning I, and five other people, are doing has already identified several problems with Connecticut's system of services that need to be addressed by the DD Council:

- we need to develop more family support resources.

- we need to apply rehabilitation engineering for better communication adaptations.

- we need to make Council resources available to small town government programs.

- we need to expand public and private insurance benefits.

- we need to expand and improve personal care attendant programs.

- we need to develop some cooperative housing and employment options.

- we need to build bridges to natural neighborhood support groups.

It is important to point out that personal futures planning can be done with anyone, no matter what their abilities. It can be done with advocates and guardians who believe people with developmental disabilities are, first of all, people.

As you consider reauthorizing the Developmental Disabilities Act, I ask that you make empowerment of individuals and families a public policy. Empowerment is what the Connecticut DD Council, Beth Mount and George Ducharme are doing with me. It is developing my capacity to determine my own needs, designing my own future for myself, my family, my neighborhood and those institutions that have an impact on my life.

PERSONAL FUTURES PLANNING
for Raymond (Todd) Kilroy and friends.

FINDING DIRECTIONS FOR CHANGE
AND LEARNING TOGETHER
HOW TO MAKE THINGS HAPPEN
for Raymond
and for the Community of Farmington/Unionville

Beginning worksheets,
February 17, 1987

Participants:
Raymond Kilroy,
Beth Mount and George Ducharme

Discover capacities

Find directions for change

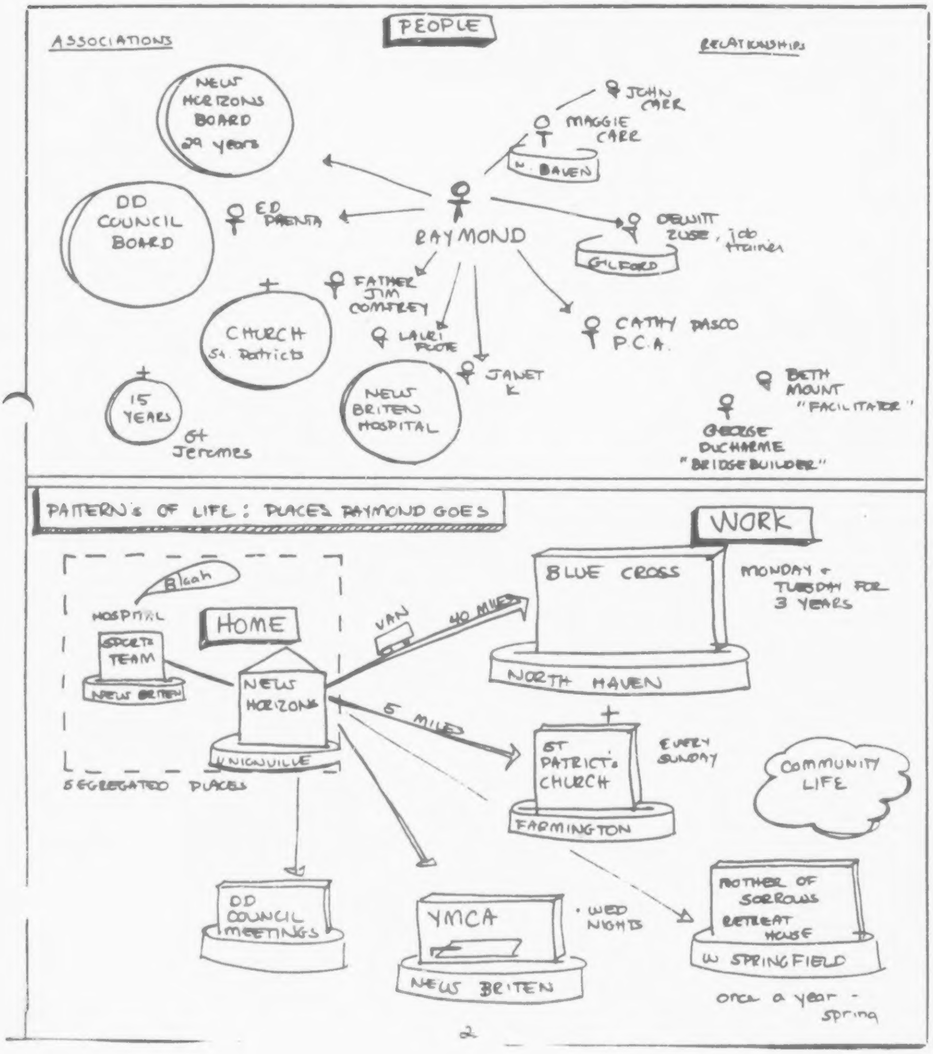
Identify obstacles and opportunities

Generate strategies

Make commitments

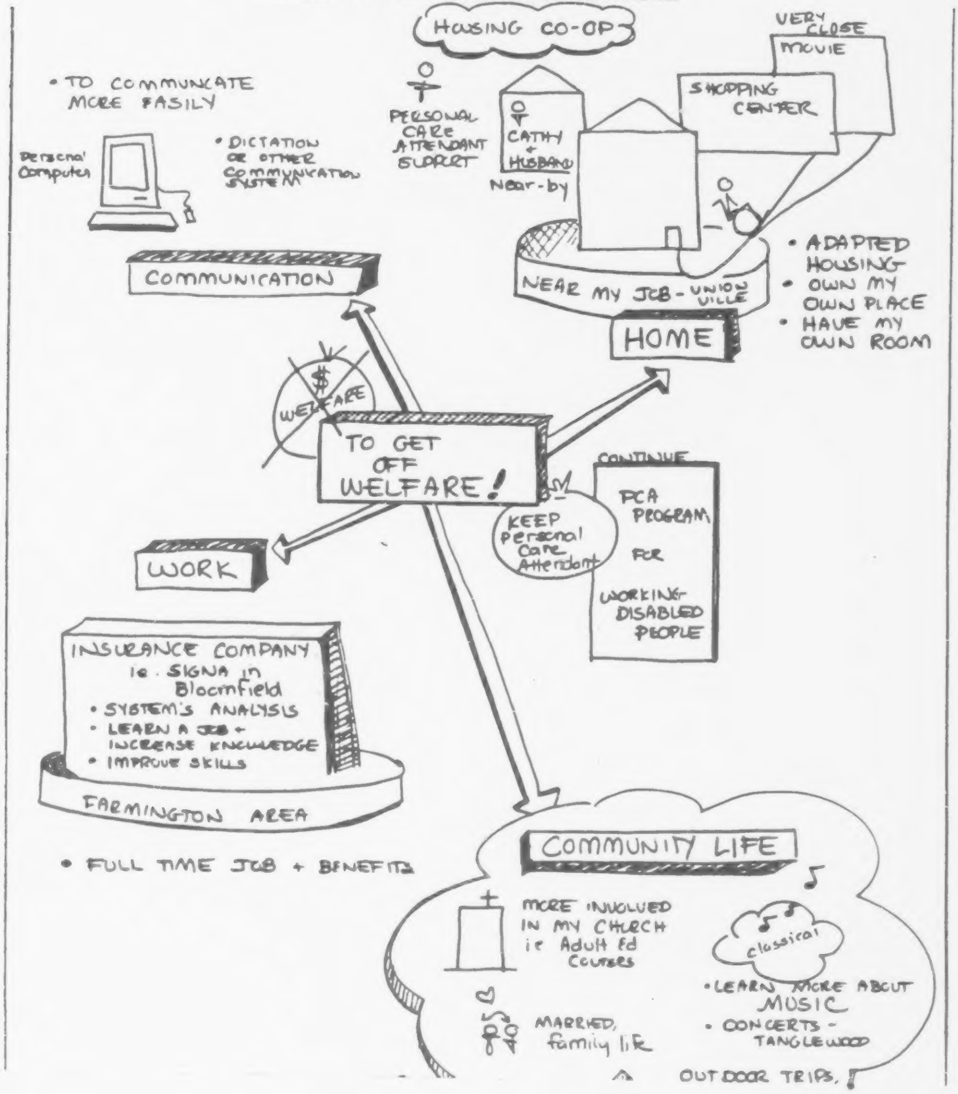
Reflect on what we are
learning together.

PATTERNS OF LIVING: SIGNIFICANT PEOPLE AND PLACES


PEOPLE
ASSOCIATIONS
RELATIONSHIPS
NEW HORIZONS BOARD 29 years
DD COUNCIL BOARD
CHURCH St. Patricks
15 YEARS
St Jeromes
NEW BRITEN HOSPITAL
RAYMOND
JOHN CARR
MAGGIE CARR
N. HAVEN
ED PRENTA
DEWITT ZUSE, job trainer
GILFORD
FATHER JIM COMFREY
LAURI FOOTE
JANET K
CATHY PASCO P.C.A.
BETH MOUNT "FACILITATOR"
GEORGE DUCHARME "BRIDGEBUILDER"
PATTERN's OF LIFE: PLACES RAYMOND GOES
WORK
Blaah
HOSPITAL
SPORTS TEAM
NEW BRITEN
HOME
NEW HORIZONS
UNIONVILLE
SEGREGATED PLACES
VAN
40 MILES
BLUE CROSS
NORTH HAVEN
MONDAY + TUESDAY FOR 3 YEARS
5 MILES
ST PATRICK's CHURCH
FARMINGTON
EVERY SUNDAY
COMMUNITY LIFE
DD COUNCIL MEETINGS
YMCA
NEW BRITEN
• WED NIGHTS
MOTHER OF SORROWS RETREAT HOUSE
W SPRINGFIELD
once a year - spring

Futures for Raymond 2/87

IMAGES OF THE FUTURE FOR RAYMOND


HOUSING CO-OP
VERY CLOSE
MOVIE
SHOPPING CENTER
• TO COMMUNICATE MORE EASILY
PERSONAL CARE ATTENDANT SUPPORT
CATHY + HUSBAND
Near-by
Personal Computer
• DICTATION OR OTHER COMMUNICATION SYSTEM
COMMUNICATION
• ADAPTED HOUSING
• OWN MY OWN PLACE
• HAVE MY OWN ROOM
NEAR MY JOB - UNION VILLE
HOME
$
WELFARE
TO GET OFF WELFARE!
CONTINUE
PCA PROGRAM FOR WORKING DISABLED PEOPLE
KEEP Personal Care Attendant
WORK
INSURANCE COMPANY ie. SIGNA in Bloomfield
• SYSTEM'S ANALYSIS
• LEARN A JOB + INCREASE KNOWLEDGE
• IMPROVE SKILLS
FARMINGTON AREA
• FULL TIME JOB + BENEFITS
COMMUNITY LIFE
MORE INVOLVED IN MY CHURCH ie Adult Ed Courses
classical
• LEARN MORE ABOUT MUSIC
• CONCERTS - TANGLEWOOD
MARRIED, family life
OUTDOOR TRIPS!

Futures for Raymond 2/87

THINGS THAT WILL HELP; OPPORTUNITIES:

- The housing co-operative idea David Wetherow's work
- An architect I know is interested in building adapted housing Maybe we can put his interests together with the housing co-operative idea
- Cathy (my current P.C.A.) and her soon-to-be husband are interested in living near-by
- Janet Klienman at Gaylord Hospital knows a lot about disability benefit/financial issues She can help
- I like my job It is the most important thing to me The help I get from Dewitt as a volunteer is really important
- I like doing system's analysis I have a desire to learn new skills and practice what I learn I want to use my MBA
- Going to the YMCA and church is really important I want to get more involved at church
- Maggie Carr is a good person to know
- Raymond's ability to write, to express himself

OBSTACLES AND FEARS:

- The co-op idea is very complex
- Housing is so expensive I need to be more careful about roommate selection
- Managing Personal Care Attendants (P.C.A.s) is challenging I need to set up a 1 to 3 month trial period before long-term contracts are finalized
- Getting off welfare while keeping benefits and the P.C.A. program is challenging I have to work full-time and have good benefits to get off welfare
- People at work don't believe I can work and take care of myself I have been on this temporary-part-time status for over 2 years
- Blue Cross relies on Dewitt too much--I'm afraid of (their) taking advantage of Dewitt.
- I have no plan for the future at Blue Cross I see no way to get off welfare as long as I am part-time
- New Horizons is better than the hospital I lived in for 30 years, but it is still too remote I want to be be a part of community life
- Talking is very hard It takes a long time to get everything out

EDWARD M. KENNEDY, CHAIRMAN

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United States Senate
COMMITTEE ON LABOR AND
HUMAN RESOURCES
WASHINGTON, DC 20510-6300

April 10, 1987

Raymond F. Kilroy
57 Bliss Memorial Drive
Unionville, CT 06085

Dear Raymond,

Thank you for testifying before the Subcommittee on the Handicapped regarding the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. Your successes are certainly an inspiration for us all and reaffirm what we already know: individuals with disabilities can accomplish much given appropriate support.

There are a number of questions to which my colleaguse of the Subcommittee and I would appreciate your response. Please provide me with your comments on the following:

1. Do you feel the emphasis placed on employment by the Developmental Disabilities Council was instrumental in helping you to get where you are today?

2. You described your involvement in very interesting planning activities through the Developmental Disabilities Council. What do you envision as the outcome of this planning?

3. What do you feel are the most important issues that the Congress should address in its reauthorization of the Developmental Disabilities Act?

4. Please comment on the Administration's proposal for a new priority of Family Support Services and how it might be beneficial to you.

5. How do you feel Congress can best address the needs of individuals with developmental disabilities who are becoming older adults?

Raymond F. Kilroy
April 10, 1987
Page Two

I look forward to receiving your responses to these questions and thank you in advance for your continued assistance to us as we consider the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. Please provide me with your written comments by April 23, 1987 when the record of the hearing will be closed.

Sincerely,

Tom Harkin

Tom Harkin
Chairman, Subcommittee on
the Handicapped

TH/kb

57 Bliss Memorial Drive
Unionville, CT 06085
April 21, 1987

Senator Tom Harkin
Chairperson
U. S. Senate Subcommittee
on the Handicapped
113 Hart Senate Office Building
Washington, D.C. 20510-6300

Dear Senator Harkin:

Thank you, and to Senator Weicker, for inviting me to testify before the Subcommittee on the Handicapped regarding the reauthorization of the Developmental Disabilities Act. I hope my responses below to your written questions of April 10, 1987 are helpful to your Subcommittee.

First, I would like to make a correction to my transcript of my testimony. On page 46, lines 12 through 15, I would like to make it clear that I first entered an institution at the age of 10 when I went to a boarding school for children with cerebral palsy in New Jersey. I was placed at New Britain Memorial Hospital at the age of 20 when I moved to Connecticut.

1. Do you feel the emphasis placed on employment by the Developmental Disabilities Council was instrumental in helping you to get where you are today?

Yes. The work the DD Council is doing in the area of employment has been very important and helpful to people with developmental disabilities. The Council's grants stimulated the development of rehabilitation engineering. Rehabilitation engineering is being used to make adaptations to the work site, thereby opening employment opportunities in a variety of fields from which a person with a developmental disability can choose. Without rehabilitation engineering, I would not have my part-time job at Blue Cross/Blue Shield of Connecticut.

The work the DD Council has done to open employment opportunities in real jobs for real wages has led to new bridges to be crossed in order for all people with disabilities to be valued, contributing members of communities. The next bridge to be crossed is to reform Medicaid (Title XIX) to eliminate disincentives to work. There is only so much a DD Council can do at the state level. In Connecticut, the DD Council was instrumental in making sure our state took advantage of the new

1619 (a) and (b) provisions in the Social Security Act. It is now possible for people with disabilities to work and earn a little more for a longer period of time and still retain eligibility for Medicaid benefits. The difficulty still remains for people to transition completely off public assistance. I do not know exactly how to reform Medicaid. It is too complex for most people to understand. However, I thought I would share with you a letter I wrote to Connecticut's Commissioner of Income Maintenance, our Medicaid agency. I hope it will encourage you to reform the Medicaid program at the Federal level to help people like me transition off public assistance.

2. You described your involvement in very interesting planning activities through the Developmental Disabilities Council. What do you envision as the outcome of this planning?

Ever since I was a boy, I have been working toward being as self-sufficient as possible. At the present time, I work part-time and I live at New Horizon's Village. New Horizon's Village is a specially designed village for people with disabilities. I was on the Board of Directors of New Horizons and had a part in the development of the village. After living at New Britain Memorial Hospital, a large institution, for twenty-nine years the transition to New Horizons Village was still a traumatic experience. The problem I experienced was that services for persons with disabilities tended to concentrate on single issue areas (e.g. housing for the disabled, employment for the disabled) one issue at a time.

With personal futures planning, first, I decide the issues that are important. I control my future. Second, I am approaching my future from a holistic point of view. I see the "big picture" and it includes a home (perhaps an apartment), not just a roof over my head. A home is a place where I make choices and choose the people with whom I will spend time. It includes learning and developing skills useful to me and to the community where I will live. It includes working, not just keeping busy, and developing relationships with co-workers. It includes making friends through contacts with many different people in many clubs and organizations in my community. All these areas are important to me at different times in my life and I choose which are important and when. With personal futures planning, I can work on issues one at a time or simultaneously.

With personal futures planning, I plan to move from New Horizons Village to an apartment, maybe even a co-operative apartment. I plan to further my career and seek a new job that allows me to work more hours. I plan to get more involved in my church and make new friends. I plan to be more self-sufficient and independent and get off public assistance.

Finally, I hope the Independent Living Centers program, funded and authorized under the Vocational Rehabilitation Act, will adopt the concept of personal futures planning.

3. What do you feel are the most important issues that the Congress should address in its reauthorization of the Developmental Disabilities Act?

I believe it is most important to expand the DD program's ability to empower individuals and families to control their own futures. To do so the DD program must be moved away from providing services toward empowering individuals and families to acquire the support they want. In addition, the DD program must move away from enhancing specialized disability organizations and facilities to adapting generic neighborhood associations. I've enclosed a flyer about an upcoming workshop sponsored by the Connecticut DD Council on Regenerating Community. This workshop is an illustration of the importance Connecticut places on building the capacities of people and neighborhoods. You may wish to get in touch with Mr. McKnight for further insight on this issue.

4. Please comment on the Administration's proposal for a new priority of Family Support Services and how it might be beneficial to you.

To be honest with you, Senator, I am not familiar with the Administration's proposal on Family Support Services. However, I am familiar with the general discussion about family support that has taken place in the disability community in regard to the reauthorization of the DD Act. Please keep in mind that I am a single person and I plan to live alone or with someone to share an apartment. I am assuming the term "family" is defined broadly enough to include people like me.

I believe individual and family support can already be addressed by DD Councils under the already existing priorities. I suggest that individual and family empowerment be one of the purposes of the DD Act and that the concept of empowerment be incorporated in the definitions of all the already existing priorities. Empowerment is not something that can be limited to one priority area. Including empowerment in all priority areas will make it possible for me, other people with disabilities, and families to control the kinds of support we can access under each priority area.

My reservations about a new priority are two-fold. First, why create a new priority if the issue can already be addressed under existing priorities? Second, there are limits to the degree government can influence families. I would not wish to establish unreal expectations.

I also have reservations about the term "case management." I know the term and concept have been difficult to understand and implement. I, personally, do not like the idea that I am a "case" to be "managed." I am a person with abilities. There are, however, many elements about "case management" that are appealing and could be helpful to individuals and families. Perhaps you would be interested in changing "case management" to "family counseling." I think this term is closer to empowering individuals and families to make choices.

5. How do you feel Congress can best address the needs of individuals with developmental disabilities who are becoming older adults?

It is already possible under the DD Act to address the issue of people with developmental disabilities who are aging and aged.

I am not yet an older adult, so I may not be the most knowledgeable person about this issue. Nevertheless, when I am "age eligible" for senior citizen services from my town, state and from federal programs I expect to be able to take advantage of all those services.

Philosophically, I have difficulty approving housing for the elderly (elderly ghettos) when it is inappropriate to group people with disabilities together in institutions. I have difficulty creating senior citizen centers (senior segregation centers) when it is better to integrate people with disabilities into natural neighborhood associations. I have difficulty doing these things that separate elderly people from families and communities when it is better to support individuals with disabilities and their families in their homes in their communities.

Assuming that public policy about people who are elderly has some catching up to do to public policy about people with disabilities, for the time being, I think it is appropriate for people with disabilities who are aging and aged to participate in existing town, state and federal programs for people who are elderly. I want to make it clear, however, I do not think it is appropriate for people with disabilities who are not elderly to live in housing for the elderly, attend senior citizen centers or ride vans for senior citizens. People with disabilities should not be made to do what is not age appropriate.

I thank you for this opportunity to submit a response to your questions.

Sincerely,

Raymond Kilroy

Raymond Kilroy

cc: Senator Lowell Weicker

Mr. Stephen B. Heintz, Commissioner
Connecticut State Department of Income Maintenance
110 Bartholomew Street
Hartford, Connecticut 06106

Dear Mr. Heintz,

I doubt if you remember me but I met you at David Brodhead's funeral service. My name is Raymond Kilroy but people call me Todd. I lived with David at New Britain Memorial Hospital but have now moved to New Horizons Village.

In October I was at the Candidates' Forum put on by the Connecticut Coalition of Citizens with Disabilities (CCCD). When Governor O'Neill spoke to the group, I brought up the issue of work incentives. I had long thought that this was a problem that has to be dealt with. A week after the Forum I received a letter from Governor O'Neill in which he said he referred this matter to you and I thought I would write you some of my thoughts on this.

Most people think of public assistance in terms of all or nothing. We have one group, liberals, which are in favor of all kinds of public assistance. The other group, conservatives, usually have a lot of doubts about public assistance. I feel that somehow people who are on public assistance have to start working with the people who administer public funding.

If you will allow me, I would like to use myself as an example of one who receives public assistance and who holds a part-time job.I have been working at Blue Cross/Blue Shield for over two years. Eventually I hope to move into my own apartment nearer to the job. It takes a lot of money to establish a disabled person in the community. I believe that for someone like myself who would like to get off public assistance there should be a procedure where they are able to come to an agreement with the state as to how the process will occur. Following are a couple of suggestions of what this process might be.

A persom might decide that it would take a number of years for them to get off public assistance. For the purpose of simplicity I will use a period of five years. After a reasonable amount is deducted from the person's salary for transportation, the remainder would be divided into three equal parts. One part would go to the individual, another part to the state and the third part would be put into an escrow fund to be used at the time when the person is able to get off public assistance. If the person was able to do this in the first year, they would take all of the escrow. If they got off in the second year they would get 80%, 60% in the third year , and so forth, and the state would get the rest. A system like this would not only motivate people to get off public assistance but it would also motivate them to do it in as short a time as possible.

Another suggestion would be to have the escrow account based on a yearly basis. At the end of each year, if the person was unable to get off public assistance, the state would receive 80% or 90% of the escrow account. The other part would remain in escrow . This would continue for an indefinite number of years.

Each person with a disability has a unique attitude toward their own disability. I know that there cannot be an individual answer for each person, but I feel that it is very important to have two or three possible plans for the person to consider.

The above suggestions are intended only as ideas, with the hope of starting a process that will lead to a more reasonable arrangement of creating work incentives,

I was a member of the Developmental Disabilities Council for eight years and a member of New Horizons' Board of Directors for 29 years. If I can be helpful to you in this matter, please feel free to call on me.

Sincerely,

Raymond kilroy
57 Bliss Memorial Drive
Unionville, CT 06085

c.c.Governor O'Neill

Senator HARKIN. Thank you very much, Todd, for that very fine testimony. I am going to be coming back to you because I have some questions about this positive futures planning.

First, I would like to ask Mrs. Wasik about your statement. As I said, it almost sounds like something out of the Dark Ages. It is almost unbelievable that that kind of thing could be going on today.

Again I would ask you just as sort of a generalized question, if the Michigan P&A had not represented your son in this case—and that is over the last couple of years, is that right——

Mrs. WASIK. Right.

Senator HARKIN. What would be his status today? Would he still be there?

Mrs. WASIK. No. My son would probably be dead. He was neglected medically, terribly.

Senator HARKIN. Do you feel that the Michigan P&A really did a good job for you?

Mrs. WASIK. Yes.

Senator HARKIN. Now, Robin, you are from the Michigan P&A?

Ms. FRIEDMAN. That is right.

Senator HARKIN. Are you the director of that?

Ms. FRIEDMAN. No, I am not. I am a supervisor in the southeast part of the State.

Senator HARKIN. I am sorry, I did not hear you. What is your role in the Michigan P&A?

Ms. FRIEDMAN. My position is area supervisor. I cover the Detroit metro area and the rest of the southeast part of the State, along with some of our other staff persons there.

Senator HARKIN. Were you involved in this case?

Ms. FRIEDMAN. Yes, I was.

Senator HARKIN. So you were fully cognizant of it.

Ms. FRIEDMAN. Yes. We became aware of the nursing home directly through a call to me, and we mobilized our staff in response to the call.

Senator HARKIN. But weren't there State laws and things that this place was violating? I mean, it just sounds like every imaginable law that I could imagine would prohibit things like this.

Ms. FRIEDMAN. We thought so, and so initially our aim was to just make sure that the laws in place and the public health code regulations were being implemented to meet that situation, and we filed a number of administrative complaints and met with public health officials and mental health officials.

Unfortunately, they claimed they did not have the ability to assure that the program at this nursing home would come up to standards, and provide a safe living environment for the children. And so despite the administrative processes and despite the other informal activities that we were involved in, in a period of weeks, things deteriorated so rapidly that we were forced to go in at a more formal level.

Senator HARKIN. Now, this was a private nursing home.

Ms. FRIEDMAN. It is a private nursing home.

Senator HARKIN. Was it just one individually, or did they have a chain of them, as so happens?

Ms. **Friedman**. This was not one of the larger chains, although in Michigan, this particular corporation did run three nursing homes, all geriatric facilities.

Senator **Harkin**. Did they permit parents or did they admit any advocate to come in there during the day, for example, to monitor what they were doing during the day? I know, Mrs. Wasik, you said that a lot of times you would come to pick up your son on the weekends, and you were not really fully cognizant of what was going on behind the walls there.

Mrs. **Wasik**. My son was contained in a room with nine other kids. It was two rooms adjoining. It is what they called their intensive care unit. And that is the only part we were allowed to go in.

Senator **Harkin**. They would not let you go through the other part?

Mrs. **Wasik**. In the other part, no.

Ms. **Friedman**. And since this was primarily a geriatric facility where a few years ago they moved in a number of children, it was not a program that was known to us, nor to the Department of Mental Health, which generally oversees the services for children in the State.

Senator **Harkin**. Robin, do you have enough funding to pursue each case that has merit that comes in the door, or must you set priorities?

Ms. **Friedman**. We have had to set priorities. The persons who are in institutions or nursing homes have become the priority for our agency right now, because of their at-risk status. And so we mobilize a lot of our staff time and agency money in that effort.

However, we have concerns about being able to continue at the level we have been going at because of the fiscal issue.

Senator **Harkin**. How many legitimate cases do you think you turn away a month, a year?

Ms. **Friedman**. So far, we have not turned any cases away. We have turned to prioritizing of issues and turned to dealing with those people who have sought our direct involvement in their problem issues, through information and referral and other technical assistance. We have prioritized in that people who are at risk are our primary clients that receive direct representation services. We do not receive enough funding to meet the demand for direct case representation.

Senator **Harkin**. This situation in this nursing home, when it was all brought out, was it publicized, was it in the local papers and television, things like that?

Ms. **Friedman**. It made the press. It did not really make television. It did not get the kind of coverage that we might have hoped for. To be perfectly honest, the local stations were not real interested in the issue.

Senator **Harkin**. I have found in cases like this, the best thing is the light of day; let it get out, and let people focus on it.

Ms. **Friedman**. It did get some news coverage, though, in the written press.

Senator **Harkin**. Ms. Friedman, after you have filed a complaint against a Government agency on behalf of a client and the case is resolved, have the persons within the agency ever shared with you any reactions to your efforts at all, any off-the-record reactions?

Have they said good, bad, indifferent, keep it up, do not keep it up--what kind of reactions?

Ms. **Friedman**. Actually, about midway through the process, we started to receive assistance from the Mental Health Department in terms of kind of insider-type information that they provided to us, which helped us, in filing the complaints. It was done off-the-record. It was done through telephone conversations that were always, "Never repeat this" at the end of sentences. So we actually were working almost cooperatively on this particular issue.

Since then, that has improved our relationships not only in that department but in other areas as well where we receive referrals from the people that sometimes we find ourselves in opposite sides of the fence situations.

Senator **Harkin**. I have some follow-up questions, but I want to ask Raymond a question, and then I will recognize Senator Stafford.

Do you have some questions, Senator Stafford?

Senator **Stafford**. Well, thank you very much, Mr. Chairman, but I simply want to compliment all three of the witnesses on their excellent statements. They will inspire us to work all the harder, and I will not ask any questions.

Senator **Harkin**. Thank you, Senator Stafford.

I just wanted to follow up with—is it Raymond or Todd? I had been told "Todd"—is it both? Which do you prefer?

Mr. **Kilroy**. Raymond.

Senator **Harkin**. Raymond. OK. I did not know which one you preferred, Mr. Kilroy.

What I mentioned today—and I had some other questions—but what caught my attention was the chart and the words "positive futures planning." Now, am I right in assuming that this is something that you just sort of did on your own, that you decided that you had to do this for yourself and did this on your own, or was this something that the Connecticut DD Council had done?

Mr. **Ducharme**. It comes out of a three-day conference that was held in Connecticut last fall, where three leaders—John McKnight from Illinois; David Wetherow from Winnipeg, and Beth Mount from Connecticut—presented this way of thinking, and Beth Mount has developed the positive futures planning, of which Raymond is now a part.

Mr. **Kilroy**. (Translated through communication board.) I think it is a great addition to the concept of independent living.

Mr. **Ducharme**. If you understood that, he said, "I think it is a great addition to the concept of independent living."

Senator **Harkin**. We are talking about something like that in the bill. I know the Consortium has recommended something about individual empowerment. So I guess we are going to look at that in terms of having it in the legislation.

Mr. **Ducharme**. The particular process is a highly visual process which, because of Beth's particular skills, is able to be seen immediately by those participating and obviously able to be shared with others.

Senator **Harkin**. I see. I have just been handed a note that says, "Futures planning is the four elements of: where am I now; where do I want to be, or where do I want to go; what do I want to do;

what are the barriers, and how can I use existing resources to achieve my goals." I like it a lot. I like it a lot.

Mrs. Everitt, just one thing. Your daughter, Chris, is age 34.

Mrs. EVERITT. Yes.

Senator HARKIN. And she is at home now.

Mrs. EVERITT. Yes.

Senator HARKIN. And she has cerebral palsy?

Mrs. EVERITT. Yes; is mentally retarded and has a chronic seizure disorder.

Senator HARKIN. And again, your concern is that there just are not that many residential facilities?

Mrs. EVERITT. Well, my major concern is that because she is functioning in a workshop, which is very bad—they are not mistreated, I do not mean that, but it is just is a deadend street; she is not going anywhere because they are not teaching her to do anything.

Senator HARKIN. Well, what happens to your daughter when you are gone?

Mrs. EVERITT. Well, she has been on the waiting list for a long time to get residential services, and she has had one thing offered to her which was highly inappropriate. It was with aggressive, assaultive people, which she could not survive.

I am hoping that because of my 25 years of advocacy and help, that somebody is going to take pity on my family and find a placement for her. But the problem is with that assumption that it could be good and it could not necessarily be good.

I would like to see a Federal funding source for community programs that we could depend upon. I mean, community-based services are not a new idea, by a longshot, but we just sort of fly by the seat of our pants. We get State funding; we get some Title XX; we get a little of this; if you are lucky, you get a waiver. We need, in my opinion—this is a very biased opinion, I realize--the same stability in Federal funding that the parents whose kids live in institutions have.

Senator HARKIN. Are you going to be around for a while, Raymond? I do not know when I have to go to the Floor, but if you do not have to leave, when this is over—we have one more panel.

Thank you all very much for your very fine testimony. You have all added very greatly to the hearing.

Mr. DUCHARME. Raymond would like to make one more statement, if he may.

Mr. KILROY. (Translated through communication board.) One of the barriers to people like me to become financially independent are the laws on wages we earn.

Senator HARKIN. I might have you tell me more about that later on. If you might draft something for us, I would like to know more about that if you could develop that later on.

Thank you very much. Thank you all.

[Responses of Ms. Friedman to questions submitted by Senator Harkin follow:]

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United States Senate
COMMITTEE ON LABOR AND
HUMAN RESOURCES
WASHINGTON, DC 20510-6300

April 10, 1987

Robin Friedman
Michigan Protection and Advocacy Service
313 South Washington Square
Lansing, Michigan 48933

Dear Robin,

Thank you for accompanying Lynn Wasik, and testifying before the Subcommittee on the Handicapped regarding the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. Your testimony was informative and helpful.

There are a number of questions to which my colleagues on the Subcommittee and I would appreciate your response. Please provide me with your comments on the following:

1. In the case Mrs. Wasik described, after first attempting resolution of the complaints through administrative channels and negotiation, you were forced to file a civil complaint in state court. In your experience, and in the experience of P&As around the country, how frequently are cases resolved informally? How frequently is litigation used?

2. Assuming that greater resources were available, please describe the kinds of additional services you would provide and/or the numbers and types of additional clients you would represent.

I look forward to receiving your responses to these questions and thank you in advance for your continued assistance to us as we consider the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. Please provide me with your written comments by April 23, 1987 when the record of the hearing will be closed.

Sincerely,

Tom Harkin
Chairman, Subcommittee
on the Handicapped

cc: Curt Decker
TH/kb

April 23, 1987

The Honorable Tom Harkin
Chairman, Subcommittee
on the Handicapped
Hart Senate Office building
Room 317
Washington, DC 20510-1502

Dear Senator Harkin:

Thank you for the opportunity to appear before you and the other members of the Subcommittee on the Handicapped. We especially appreciated the opportunity to share with you a small portion of our work on behalf of persons with developmental disabilities. In responding to your questions I submit the following:

1. The philosophy of the Michigan Protection and Advocacy Services is to attempt to resolve cases with the least possible intervention. I am attaching our statistics from FY 1985 and through the third Quarter of 1986 on time spent on cases resolved at various intervention levels. I understand that P&A's around the country report having the same experience. The FY 1985 and 1986 report to Congress by the Administration on Developmental Disabilities (DHHS) confirm that only between 2% and 5% of all Protection and Advocacy cases result in litigation. As Gayla Peach of Kentucky recently stated to the Home Subcommittee on Health and Environment:

> It is the philosophy of our agency to resolve clients' complaints at the lowest level possible utilizing the court as the last avenue of resolution. We litigate less than 2% of our client's complaints. However, we have a deep sense of failure when an unresponsive and often neglectful service system forces us to pursue the lengthy remedy of the court.

2. If greater resources were available to our agency and other P&A's, we would be able to reduce waiting lists for advocacy services which have begun to grow due to increased demands for our services. P&A's would be able to continue to outreach and serve several populations who are not receiving their fair share of P&A services. Thse populations include persons with developmental disabilities who:

   1. reside inappropriately in nursing homes
   2. come in contact with the criminal justice system
   3. reside in rural areas and other hard to reach localities
   4. are members of minority groups

Protection and Advocacy Systems could also expand the monitoring of larger facilities for persons with the developmental disabilities which has been a priority of the agencies since the 1984 amendments.

Again, The Michigan Advocacy Service thanks you for your support and interest in our program.

Very truly yours,

Robyn Friedman

Robyn Friedman,
Michigan Protection and Advocacy Service

% of TIME SPENT ON CASES RESOLVED AT VARIOUS INTERVENTION LEVELS
YEAR-TO-DATE

The problem encountered by the clients of the Michigan Protection and Advocacy Service are resolved at a variety of intervention levels. This chart shows the percentage of casework time spent on cases closed at each intervention level.

1985

Referral	1%
Information Only	5%
Trained for Self Help	9%
Supervised Referral, Legal Research	3%
Informal Resolution	8%
Informal Resolution & Training	12%
Negotiation/Compromise	7%
Negotiation/Compromise & Training	9%
Formal Procedure	5%
Formal Procedure & Training	11%
Lawyer Required	2%
Litigation	2%
No Resolution	9%
Other	17%

% of TIME SPENT ON CASES RESOLVED AT VARIOUS INTERVENTION LEVELS YEAR-TO-DATE

The problem encountered by the clients of the Michigan Protection and Advocacy Service are resolved at a variety of intervention levels. This chart shows the percentage of casework time spent on cases closed at each intervention level.

1986	
Referral	2%
Information Only	6%
Trained for Self Help	11%
Supervised Referral, Legal Research	4%
Informal Resolution	4%
Informal Resolution & Training	14%
Negotiation/Compromise	3%
Negotiation/Compromise & Training	8%
Formal Procedure	3%
Formal Procedure & Training	25%
Lawyer Required	1%
Litigation	5%
No Resolution	3%
Other	11%

Senator HARKIN. Our last panel is Dr. Alfred Healy, Director of the Division of Developmental Disabilities at the University of Iowa Hospital School; Judy Hoyt of Holland, Massachusetts, and Dr. Elizabeth Boggs, on behalf of the Consortium for Citizens with Developmental Disabilities.

Again, thank you all for coming, and as with the other panelists, your testimony will be made a part of the record in its entirety. We will just go down the list—Dr. Healy first, then Mrs. Hoyt and Dr. Boggs.

Dr. Healy, again welcome, thank you for coming, and we look forward to your testimony. Please proceed.

STATEMENT OF DR. ALFRED HEALY, DIRECTOR, DIVISION OF DEVELOPMENTAL DISABILITIES, UNIVERSITY HOSPITAL SCHOOL, UNIVERSITY OF IOWA; JUDY HOYT, HOLLAND, MA, AND DR. ELIZABETH M. BOGGS, ON BEHALF OF CONSORTIUM FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES

Dr. HEALY. Thank you, Senator.

I am here today representing the American Association of University-Affiliated Programs as Director of the UAF Program at the University of Iowa. Three decades ago, the lid was pried off a real can of worms that contained the inhuman and intolerable conditions that persons with mental retardation, developmental disabilities and mental illness were forced to live in in the large, impersonal warehouses we called "institutions" in this country.

The Congress assumed a very lead role in solving that problem and bringing creative solutions to it. And those solutions included not only the exposure of such inhumane care, but truly giving the people who were forced to live in those situations the opportunity to gain and demonstrate the competence and the skills that they truly did have as they left the institutions and came into our residential programs and community-based services.

They were permitted to begin to "live" in this world as opposed to "existing" in this world.

Starting with Public Law 88-164 and most recently in P.L. 98-527, Congress has provided a concept of capacity building not only for the persons with disabilities, but for the system of care upon which they rely. A four-part system was devised including the UAF system, the State Planning Council system, the State P&A system, and those relating to special projects. This allowed all of the needs of persons with disabilities to join together in all of the services required—not only data collection and analysis, but the program planning components, the client protection, student training, service programs, technical assistance, and the dissemination of research information.

The UAF component of these functions emphasizes preparation of students, in-service education of professionals, the provision of exemplary services to infants, children and adults with developmental disabilities. Another very important function is to detect the required changes in the system of care and to provide the technical assistance to the communities so that they can put together the programs that are needed to respond to those changes that are occurring in the needs of persons with disabilities.

It is important for you to understand that the UAFs accomplish these tasks by using the core administrative funding provided through this legislation, but also through the additional dollars that are leveraged by these core administrative funds. We derive extra funds through Federal, State and private sources. We can document that for every dollar spent through the Developmental Disabilities Act relating to the university-affiliated facilities, approximately $16 in additional sources are garnered to assist in providing services to this population under discussion today.

As we have addressed those statutory responsibilities, we have also identified an increasing number of new problems as we work on the resolution of the old ones. Let me try and explain at least one scenario that I think you would be interested in.

The original concern was related to the inappropriate housing of people within institutions. The solution advanced was to move those people from institutional settings to those of residential care settings that more appropriately could look after their needs.

It became very apparent there were very few appropriate programs available at the community level. One of the major problems was that there were few appropriately trained personnel, both professional and para-professional, available to provide those services. The solution advanced was to train more people. Obviously, as those people entered into the system, more trainees were required because additional services were needed. It became a very interesting situation in which, as you advanced the capacity of people who never had services provided to them in the past, they demonstrated increasing abilities that required further training from both professionals and para-professionals, which required additional training programs.

So we have an increasing escalation of need as we accomplish our stated purpose.

Three years ago in testifying before this Subcommittee, I brought to your attention concerns regarding employment, housing, training, and the need for increased technology for persons with disabilities as suggested to us by Raymond's use of his voice synthesizer today.

Today I must direct your attention to the ever-increasing incidence of young children experiencing mental retardation and other disabilities from the AIDS virus; the increasing number of adults with developmental disabilities who also themselves are aging; the lack of community delivery systems; and the slowly occurring changes in often devastating community attitudes toward persons with disabilities that appear to be occurring at a maddeningly slow pace.

But just as important is the question: What will we bring to you in another three years? Surrogate parenthood in families with identified disability-inducing genes? Prevention of disabilities through recombinant DNA and gene-splicing?

The aging of the parents of currently disabled adults, resulting in an ever increasing gap in the availability of high-quality, community-based housing for these persons with disabilities?

Each represents concerns that have been recently identified and will soon cry out for further identification and solution. Issues such as these will combine with other issues that I cannot yet even fathom, and they will join those we have been trying to solve for the past 30 years.

Therefore, there is a need for an ongoing, adequately funded, university-based process to monitor the ever-changing field of developmental disabilities and to assure appropriate responses to these changes. The system now operational under the current DD legislation has been effective in identifying the major problems and targeting resources to accomplish their resolution.

I respectfully remind the Committee that the Congress has a 30-year history of crafting effective solutions to the needs of these Americans, most notably in the four programs represented in the Developmental Disabilities Act.

I urge you to continue this winning record through reauthorization of this legislation.

I thank you very much for having the opportunity of sharing these concerns with you and I stand ready to answer any questions.

Thank you.

[The prepared statement of Dr. Healy and responses to questions submitted by Senator Harkin follow:]

TESTIMONY

Presented to:

United States Senate
Committee on Labor and Human Resources
Subcommittee on the Handicapped

Honorable Tom Harkin, Chairman

1987 REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

Respectfully Submitted by:

Alfred Healy, M.D., Director
Iowa University Affiliated Facility
Iowa City, Iowa

Representing the American Association of University Affiliated
Programs for Persons with Developmental Disabilities (AAUAP)

MR. CHAIRMAN, I AM ALFRED HEALY, A PROFESSOR OF PEDIATRICS AND OF SPECIAL EDUCATION AT THE UNIVERSITY OF IOWA. I AM HERE TODAY REPRESENTING THE AMERICAN ASSOCIATION OF UNIVERSITY AFFILIATED PROGRAMS. DURING 1985-86 THE UAF NETWORK TRAINED 35,000 STUDENTS, 10,000 PRACTITIONERS AND SERVED 70,000 PERSONS WITH DISABILITIES THROUGH ITS 53 MEMBER PROGRAMS.

THREE DECADES AGO, THE LID WAS PRIED OFF A CAN OF WORMS CONTAINING THE INTOLERABLE, INHUMAN CONDITIONS IN WHICH PERSONS WITH MENTAL RETARDATION, DEVELOPMENTAL DISABILITIES AND MENTAL ILLNESS WERE FORCED TO LIVE IN LARGE, IMPERSONAL WAREHOUSES CALLED INSTITUTIONS IN THIS COUNTRY.

THE CONGRESS ASSUMED A LEAD RESPONSIBILITY IN EXPOSING THIS SITUATION WHICH HAD TWO MAJOR OUTCOMES:

--THE INAPPROPRIATE CARE WAS EXPOSED FOR THE WORLD TO SEE.

--BUT MOST IMPORTANTLY, THE PEOPLE BEING MAINTAINED IN SUCH CARE WERE NOW PERMITTED TO DEMONSTRATE THEIR COMPETENCE TO LEARN, TO GAIN SKILLS, AND CONTRIBUTE TO THE WORLD THEY WERE IN, BUT UNFORTUNATELY, WERE NOT LIVING IN.

JUST AS CONGRESS PARTICIPATED IN IDENTIFYING THE PROBLEM, THEY ALSO PARTICIPATED IN CREATING THE SOLUTION TO THIS PROBLEM. STARTING WITH PL 88-164, AND MOST RECENTLY IN PL 98-527, CONGRESS PROVIDED A CONCEPT OF "CAPACITY BUILDING" BOTH FOR PERSONS WITH DEVELOPMENTAL DISABILITIES AND ALSO FOR THE SYSTEM OF CARE FOR SUCH PERSONS.

A ~~THREE~~ four PART SYSTEM WAS DEVISED CONSISTING OF UNIVERSITY AFFILIATED PROGRAMS, STATE PLANNING COUNCILS, AND STATE PROTECTION AND ADVOCACY SYSTEMS. COOPERATION BETWEEN THE THREE COMPONENTS PERMITTED INTEGRATION OF THE FUNCTIONS OF DATA COLLECTION AND ANALYSIS, PROGRAM PLANNING, CLIENT PROTECTION, STUDENT TRAINING, SERVICE PROGRAMS, TECHNICAL ASSISTANCE, AND DISSEMINATION OF RESEARCH INFORMATION.

THE UAF COMPONENT OF THOSE FUNCTIONS HAS EMPHASIZED PREPARATION OF UNIVERSITY & COLLEGE STUDENTS TO WORK WITH PERSONS WITH DEVELOPMENTAL DISABILITIES; TO PROVIDE IN-SERVICE EDUCATION TO THOSE ALREADY IN PRACTICE; AND TO EVALUATE AND TREAT INFANTS, CHILDREN AND ADULTS WITH DEVELOPMENTAL DISABILITIES. ANOTHER IMPORTANT FUNCTION IS TO DETECT REQUIRED CHANGES IN THE SYSTEM OF CARE FOR PERSONS WITH DISABILITIES AND THEIR FAMILIES AND TO MEET THOSE NEW NEEDS THROUGH THE PROVISION OF TECHNICAL ASSISTANCE TO COMMUNITY PROGRAMS.

UAF'S ACCOMPLISH THESE TASKS BY USING CORE ADMINISTRATIVE FUNDING PROVIDED THROUGH PL 98-527, BUT ALSO THROUGH THE ADDITIONAL DOLLARS "LEVERAGED" FROM OTHER FEDERAL, STATE AND PRIVATE FUNDING SOURCES. FOR EVERY CORE UAF DOLLAR, AN ADDITIONAL SIXTEEN DOLLARS ARE GENERATED FROM THESE NON-UAF SOURCES.

AS THE UAF'S HAVE ADDRESSED THEIR STATUTORY RESPONSIBILITIES, THEY HAVE IDENTIFIED AN EVER INCREASING SERIES OF NEW PROBLEMS AS THEY WORK ON THE RESOLUTION OF EXISTING CONCERNS. EACH NEW SOLUTION IDENTIFIES ANOTHER, YET-TO-BE RESOLVED PROBLEM.

LET ME EXPLAIN. THE ORIGINAL CONCERN WAS INAPPROPRIATE INSTITUTIONALIZATION. THE SOLUTION ADVANCED WAS COMMUNITY, RATHER THAN INSTITUTIONAL PLACEMENT. IT BECAME APPARENT THERE WERE FEW APPROPRIATE COMMUNITY HOUSING OR VOCATIONAL PROGRAMS AVAILABLE. THE SOLUTION SUGGESTED WAS TO CREATE NEW HOUSING AND PROGRAMMING. AS THIS WAS ATTEMPTED THE LACK OF ADEQUATELY TRAINED DIRECT CARE WORKERS, SOMETIMES REFERRED TO AS PARAPROFESSIONALS, WAS RECOGNIZED. EVEN AS NEW TRAINING PROGRAMS WERE STARTED IT SOON BECAME EVIDENT THE REAL PROBLEMS WERE LOW WAGES AND THE EXTREMELY LOW SOCIETAL PRESTIGE ASSOCIATED WITH SUCH POSITIONS. TO FURTHER COMPLICATE THE ISSUE, INCREASING THE TRAINING AND EDUCATION OF PERSONS WITH DISABILITIES OFTEN DEMONSTRATES THEIR INCREASED

CAPACITY TO LEARN, WHICH REQUIRES DIRECT CARE WORKERS AND PROFESSIONALS TO INCREASE THEIR OWN SKILLS--WHICH REQUIRES INCREASED PERSONNEL TRAINING --WHICH REQUIRES INCREASED TRAINING PROGRAMS--THE LIST GOES ON AND ON.

THREE YEARS AGO IN TESTIFYING BEFORE THIS SUBCOMMITTEE I BROUGHT TO YOUR ATTENTION CONCERNS REGARDING EMPLOYMENT, HOUSING, TRAINING, AND THE NEED FOR INCREASED TECHNOLOGY FOR PERSONS WITH DISABILITIES. TODAY, I MUST DIRECT YOUR ATTENTION TO THE EVER INCREASING INCIDENCE OF YOUNG CHILDREN EXPERIENCING MENTAL RETARDATION AND OTHER DISABILITIES SECONDARY TO THE AIDS VIRUS; THE INCREASING NUMBER OF ADULTS WITH DEVELOPMENTAL DISABILITIES WHO ARE ALSO AGING--AND COMPOUNDING THEIR DISABILITIES IN WAYS CONFUSING TO EVEN OUR BEST CLINICIANS AND RESEARCHERS; THE LACK OF COMMUNITY SERVICE DELIVERY SYSTEMS, INCLUDING UNREALISTIC FINANCING MECHANISMS; AND DEVASTATING COMMUNITY ATTITUDES TOWARD PERSONS WITH DISABILITIES.

BUT JUST AS IMPORTANT IS THE QUESTION, "WHAT WILL THE PROBLEMS BE IN ANOTHER THREE YEARS?" SURROGATE PARENTHOOD IN FAMILIES WITH IDENTIFIED DISABILITY-INDUCING GENES? PREVENTION OF DISABILITIES THROUGH RECOMBINANT DNA AND GENE SPLICING? THE AGING OF THE PARENTS OF CURRENTLY DISABLED ADULTS, RESULTING IN AN EVEN LARGER GAP IN THE AVAILABILITY OF HIGH QUALITY, COMMUNITY-BASED HOUSING FOR THEIR DISABLED CHILDREN? EACH REPRESENTS CONCERNS THAT HAVE BEEN RECENTLY IDENTIFIED AND WILL SOON CRY OUT FOR FURTHER STUDY.

ISSUES SUCH AS THESE WILL COMBINE WITH OTHER ISSUES I CAN'T EVEN CURRENTLY FATHOM -- AND THEY WILL JOIN THOSE WE HAVE BEEN ADDRESSING FOR THE PAST THIRTY YEARS.

THEREFORE, THERE IS A NEED FOR AN ONGOING UNIVERSITY-BASED PROCESS TO

MONITOR THE EVER-CHANGING FIELD OF DEVELOPMENTAL DISABILITIES AND TO ENSURE APPROPRIATE RESPONSES TO THOSE CHANGES. THE SYSTEM NOW OPERATIONAL UNDER THE CURRENT DD LEGISLATION HAS BEEN EFFECTIVE IN IDENTIFYING THE MAJOR PROBLEMS AND TARGETING RESOURCES TO ACCOMPLISH THEIR RESOLUTION.

I WILL CLOSE THIS TESTIMONY BY REMINDING THE COMMITTEE THAT THE CONGRESS HAS BEEN OF TREMENDOUS ASSISTANCE TO SOCIETY IN THE IDENTIFICATION OF THE VAST NEEDS OF PERSONS WITH DEVELOPMENTAL DISABILITIES, AND THAT YOU HAVE A THIRTY YEAR HISTORY OF CRAFTING EFFECTIVE SOLUTIONS TO THE NEEDS OF THESE AMERICANS, MOST NOTABLY IN THE ~~THREE~~ four PROGRAMS REPRESENTED IN THE DEVELOPMENTAL DISABILITIES ACT. I URGE YOU TO CONTINUE THIS WINNING RECORD THROUGH REAUTHORIZATION OF THIS LEGISLATION.

THANK YOU FOR THE OPPORTUNITY TO SHARE THESE CONCERNS WITH YOU TODAY.

Alfred Healy M.D.
Professor of Pediatrics
College of Medicine
Professor of Special Education
College of Education
University of Iowa

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United States Senate
COMMITTEE ON LABOR AND
HUMAN RESOURCES
WASHINGTON, DC 20510-6300

April 10, 1987

Alfred Healy, M.D.
Director
Division of Developmental Disabilities
University Hospital School
University of Iowa
Iowa City, Iowa 52242

Dear Dr. Healy,

Thank you for testifying before the Subcommittee on the Handicapped regarding the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. It was a pleasure to have you as a witness, and your testimony was very informative and helpful.

There are a number of questions to which my colleagues on the Subcommittee and I would appreciate your response. Please provide me with your comments on the following:

1. Written testimony presented by the American Association of University Affiliated Programs for persons with developmental disabilities states that UAFs generate $16 for each $1 of funding under the Developmental Disabilities Act. Of the $16, how much is targeted on severely handicapped persons with developmental disabilities, as the term is used in the Developmental Disabilities Act, as compared with more moderately handicapped persons in general?

2. My staff has heard assertions that some UAFs located in medical schools are not doing enough interdisciplinary training. That is, the approach in these settings is described as too medically oriented with not enough is emphasis on training for psychologists, social workers, and nutritionists. What is your response to these assertions?

3. Your testimony summarized very aptly the situation we face in all aspects of our search to provide the support necessary to enable individuals with disabilities of all types and all ages to achieve a good quality of life---our newest solutions yield still more challenges. How important is the developmental disabilities system in keeping us on the "cutting edge" of those problems, solutions, and challenges?

Alfred Healy, M.D.
April 10, 1987
Page Two

4. How would you assess the current status of technical assistance provided by University Affiliated Facilities? Specifically,

a) How many University Affiliated Facilities are providing technical assistance?

b) Which agencies most often request technical assistance from UAFs?

c) What type of assistance do most agencies require?

I look forward to receiving your responses to these questions and thank you in advance for your continued assistance to us as we consider the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. Please provide me with your written comments by April 23, 1987 when the record of the hearing will be closed.

Sincerely,

Tom Hark

Tom Harkin
Chairman, Subcommittee
on the Handicapped

cc: Al Guida
TH/kb

aauap
American Association of University Affiliated Programs for Persons with Developmental Disabilities

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President

Ansley Bacon-Prue, Ph.D.
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Member at Large

Jane Rues, Ed.D.
Member at Large

Hill Walker, Ph.D.
Member at Large

William E. Jones, Ph.D.
Executive Director

April 23, 1987

Sen. Tom Harkin
Atten: Bob Silverstein
SH 113 Hart Senate Office Building
Washington, D.C. 20510

Dear Mr. Silverstein:

Enclosed please find the responses to questions that Sen. Harkin directed to me in his letter of April 10, 1987. I hope they are helpful.

Because of the short time period, I was not able to respond with hard empirical data to certain questions. Specifically, question #1 concerning the number of severely handicapped persons with developmental disabilities who we serve with our non-DD Act funding and question #2 relating to our technical assistance activities involved data that the Administration on Developmental Disabilities does not require us to collect presently.

However, I have commissioned the AAUAP Database Committee to conduct an internal survey of the network in order to provide Sen. Harkin with the requested information. We hope to have that data gathered and assessed within two or three weeks. While it will not be available in time for insertion into the formal hearing record, I feel that the information will nontheless be valuable input for the Handicapped Subcommittee's substantive decision-making process.

I enjoyed testifying before the Subcommittee. Thank you for your kind consideration.

Sincerely,

Al Healy
Alfred Healy, M.D.
Director
Iowa University Affiliated Facility

Enclosure

8605 Cameron Street, Suite 406 • Silver Spring, Maryland 20910 • (301) 588-8252

April 23, 1987

RESPONSES TO QUESTIONS SUBMITTED BY SENATOR TOM HARKIN ON BEHALF OF THE SENATE SUBCOMMITTEE ON THE HANDICAPPED, OF THE COMMITTEE ON LABOR AND HUMAN RESOURCES

QUESTION 1. Written testimony presented by the American Association of University Affiliated Programs for Persons with Developmental Disabilities states that UAFs generate $16 for each $1 of funding under the Developmental Disabilities Act. Of the $16, how much is targeted on severely handicapped persons with developmental disabilities, as the term is used in the Developmental Disabilities Act, as compared with more moderately handicapped persons in general?

ANSWER 1. In order to address this question, it is first necessary to acknowledge the considerable variation that exists among individual UAFs. As you know, PL 98-527 provides core administrative funding for University Affiliated Facilities to provide four primary functions: 1) interdisciplinary training, 2) exemplary services, 3) technical assistance, and, 4) dissemination of research findings. Although each function plays a major role in accomplishing the full intent of the legislation, neither historic nor legislative direction has been given to the relative proportion each UAF should devote to the four functions.

Because of the widely divergent university settings in which UAFs exist, each UAF possesses a unique set of characteristics that permits it to capitalize on the strengths of the university with which it is affiliated. Therefore, as individual centers of excellence, UAF's demonstrate relative asymmetry in the proportion of effort they devote to accomplishment of each of the four mandated functions. A consortium of special efforts is therefore available to a geographic area for application to the overall problems of the DD population. The increased funds "leveraged" by UAFs from federal non-DD sources, and state and private funds reflect such individual UAF variation. Some UAFs capitalize on their interdisciplinary training capacity, while others utilize their expertise in exemplary service delivery to garner additional program funds.

As a general statement, there are significantly more non-PL 98-527 funds devoted to the mild and moderately disabled populations available to UAFs than are funds available to support activities for the severely disabled. As each UAF seeks program funds which are not provided in the basic UAF grant under PL 98-527 to support their mandated responsibilities of teaching and provision of services, UAFs must seek grants and contracts that relate to the entire spectrum of severity -- including persons with severe disabilities.

In addition, a wide continuum of students in a variety of professions receive interdisciplinary training experiences in UAFs. UAFs are obligated to ensure students receive training in a spectrum of disabilities representing all degrees of severity. (NOTE: There is a natural tendency for some advocacy groups to envision the "severe" cohort of the DD population as representing only those with cognitive deficits.

QUESTION 2. My staff has heard assertions that some UAFs located in medical schools are not doing enough interdisciplinary training. That is, the approach in these settings is described as too medically oriented with not enough emphasis on training for psychologists, social workers, and nutritionists. What is your response to these assertions?

ANSWER 2. There are two basic assumptions in the definition of the "interdisciplinary" concept: 1) the interrelated educational, psychosocial, and health needs of persons with developmental disabilities are broader than the ability of any one discipline to meet, and 2) there must be a mutual respect for the competency, and an understanding of the roles, of all professionals and paraprofessionals providing such services. In addition, these needs must be identified through an evaluation process and the creation of a service plan that must be implemented, monitored and changed as necessary. Therefore, many different professionals as well as the person with a disability and their family must be involved in that service process if it is to successfully meet all such needs.

All UAFs understand these basic assumptions. To assure that these assumptions are implemented, each UAF undergoes a periodic rigorous ADD peer review prior to funding and must demonstrate such understanding through demonstration of both exemplary services (interdisciplinary in nature) and through interdisciplinary training programs. Those UAFs that do not demonstrate such capacity are provided opportunities to change their orientation to training or service programs or else lose ADD support.

The initial impetus to serve persons through university functions came from programs based in medical schools. As the interdisciplinary process was developed and expanded, schools of social work, education and other related disciplines became involved in the overall care of the disabled. As the UAF system expanded to include disciplines in addition to medicine, concern for the problem of "role release" was noted not to be restricted to the discipline of medicine. Just as programs that have their primary affiliation with medicine must provide a spectrum of health and non-health oriented services, so do educational oriented UAFs need to demonstrate their understanding of the need for health oriented services for those in their care, as well as to demonstrate concern for the needs of the disabled persons family in all their training and service activities.

Moreover, in general UAFs located in medical schools receive funding from the Division of Maternal and Child Health (DMCH). The program guidelines used by the agency to determine whether an individual facility merits continued funding specifically requires minimum faculty and staffing patterns for a number of disciplines including psychology, social work and nutrition. In fact, ADD and DMCH demand detailed data on the trainees we produce. This information, which is in part listed below, shows that both UAFs located in medical schools and those affiliated with educational institutions provide intensive interdisciplinary training (i.e. more than 500 hours of instruction) to a full range of allied health professionals. The nationwide statistics are as follows:

Pediatrics	694
Dentistry	402
Nursing	685
*Psychology	433
Speech Pathology	537
Audiology	114

*Social Work	320
*Nutrition	226
Physical Therapy	341
Occupational Therapy	152
Rehabilitation Counseling	105

Finally, note that these numbers do not meet our national requirements in many specific disciplines. In short, the real issue is not the "medical orientation" of certain UAFs, but rather the funding levels necessary to increase our output in each of the disciplines listed above and many others.

QUESTION 3. Your testimony summarized very aptly the situation we face in all aspects of our search to provide the support necessary to enable individuals with disabilities of all types and all ages to achieve a quality of life--our newest solutions yield still more challenges. How important is the developmental disabilities system in keeping us on the "cutting edge" of those problems, solutions and challenges?

ANSWER 3. In my opinion, the four programs operational under PL 98-527 are all critical components of a system to keep us, as a nation, on the "cutting edge" of problems, solutions and challenges relating to all aspects of the needs of persons with developmental disabilities.

There can be no question that persons with disabilities are persons with the same rights as all citizens, and that these rights entitle them to a fair and equitable opportunity to develop their abilities to the fullest possible extent. Their rights as citizens must be backed by a system that guarantees the full expression of those rights, or their rights becomes a sham. Such a DD system must therefore be comprehensive in scope, applicable to individual need, anticipatory in nature, and protective whenever necessary. The current Developmental Disability Act provides the necessary component parts for such a national system.

The current DD structure is comprehensive, systematic, capable of individualization, protective and possesses the potential for innovation. It encompasses a planning function (State Planning Councils); a training, service, technical assistance and information dissemination system (UAFs); a protection and advocacy system (State Protection & Advocacy Agencies); and a system that has the potential to support innovation and model program generation (Special Projects). Although the basic structure is present to permit an effective operational process to occur, however, the system lacks certain critical elements that would permit it to become an optimal, exemplary process to maintain "cutting edge" characteristics.

UAF's possess the critical characteristics required for a program to remain on the cutting edge of any issue relating to the disabled--primarily because they all are associated with major universities whose prime responsibility is to be innovative and challenging and to transmit the results of such innovation to their students in both preservice and inservice contexts. The major issue is, however, although UAF's possess the potential to monitor and sense the directions required for exemplary programs to proceed, they often lack the resources necessary to fulfill such a role. Core administrative funding is not sufficient to permit a comprehensive leadership role for a UAF in a statewide program.

The Administration on Developmental Disabilities has often served on the cutting edge of evolving issues. Excellent examples of this include concern for aging of persons with disabilities and supported employment. Each of these issues have been recognized by a large portion of the UAF network and now represent current program initiatives. However, as they surfaced as initiatives for action there were no new program dollars available to initiate the required program services. Each new program represent either dollars taken from other ongoing programs or dollars initiated thereby garnered from "leveraged" sources.

In summary, the system as outlined in the current legislation has the general potential to keep the nation on the "cutting edge" of the needs for persons with disabilities, but it currently lacks funding appropriate to the need. Perhaps language mandating enhanced cooperative efforts around "cutting edge" issues between DD Councils, P & As and UAFs might also be in order.

QUESTION 4. How would you assess the current status of technical assistance provided by University Affiliated Facilities.

a) How many University Affiliated Facilities are providing technical assistance?

b) Which agencies most often request technical assistance from UAFs?

c) What types of assistance do most agencies require?

ANSWER #4:

Teaching, service, and research are the foundations of modern university functions and are inherent in the job descriptions of university personnel. UAF faculty and staff traditionally have been engaged in or support one or a combination of those functions. Considerable logic was expressed in the original UAF legislation when universities were chosen as the focus (and locus) of service, training and research directed toward resolving the needs of persons with disabilities.

In 1984, PL 98-5277 added the provision of technical assistance as a prime function to the existing service, training and research dissemination functions without additional resources. In many instances this called for those with technical knowledge, but not the training or experience in transmitting that knowledge, to serve as providers of technical assistance. Other UAF's, after securing program dollars to supplement their core administrative funding, were able to hire new personnel, or train existing personnel to provide such services. Therefore, there was a certain "lag time" between the mandate and the initiation of technical assistance of similar quality to the existing exemplary service, interdisciplinary training and research dissemination activities. As a sufficient population pool of appropriately trained personnel is now available and have been incorporated into the UAF technical assistance provision system, there generally is a sufficient level of high quality technical assistance available through the UAF system to meet the request for such service.

a) All UAFs provide technical assistance. It is either in the form of consultation to state agencies, community program, or individual practitioners. Some UAFs provide national or regional advice and assistance.

b) This is entirely dependent upon individual states. Those requesting assistance frequently include State Educational Agencies (SEAs), Local Education Agencies (LEAs), State Title V Agencies (MCH & CC), Advocacy groups, State Planning Councils, community residential and vocational program, and privately funded service programs. Agencies infrequently requesting such assistance include Vocational Rehabilitation Agencies, and agencies advocating for retention of institutional placements for persons with disabilities.

c) Most agencies require fundamental assistance in needs assessment, program evaluation, and program change in response to evaluation findings. Although the needs of the agencies are relatively uncomplicated, effective technical consultation requires a certain level of experience and technical knowledge. Typical issues relate to statewide planning, adoption of state-of-the-art residential and vocational program practices, training of direct care workers, management of complicating behaviors in patients (clients, students), grant writing, interagency cooperation, and obtaining of appropriate financing.

e:ag:question

Senator HARKIN. Thank you very much, Dr. Healy. I will have a couple of questions, but again like the last panel, let us just go right down the line.

Mrs. Hoyt, welcome to the Committee, and if you would please summarize your testimony, it would be most appreciated.

Mrs. HOYT. Okay. Mr. Chairman and Members of the Committee, I am Judy Hoyt, and I am happy to be here.

I am the mother of three sons. I am a Governor's appointee to the Massachusetts Developmental Disabilities Council. I am speaking today on behalf of United Cerebral Palsy Associations, Incorporated, Epilepsy Foundation of America, and seven other national organizations on behalf of individuals with the most severe disabilities.

My remarks today will be to paint for you a portrait of an American family—my very own family. The portrait is typical of thousands of families across the country who have sons and daughters with substantial functional limitations as defined in the Developmental Disabilities Act.

Please bear in mind, there are millions of moms out there just like me. I come from a small town in Holland, Massachusetts. My firstborn child has brain damage from a face presentation at birth. He cannot walk, talk, or feed himself, and yet he has above-average intelligence. Locked in his body since birth, at eight months of age we were told, "Your son is a vegetable. Put him away."

We said, "No way. We love him. We are his parents."

Rick has described himself for you, and he uses a machine similar to Raymond's, but uses his head and clicks switches with his head in order to talk to us and type to us. What he has to say to you is as follows:

"I was about four or five years old when I knew that I could not do what my two younger brothers could. Physically, I could not move as they could; verbally, I could not speak. At first I felt cheated and angry. Even though my parents talked to and treated me the same as my brothers, I felt and knew I was different."

"My parents would read and explain what things were to me. I could only respond by a sound which sounded the same all the time. When people realize I can respond by using my mechanical communicator called 'TIC', they are most surprised. I understand all things said to me. Shell Western Being a nonvocal person does not make one any less of a human being. I have the same feelings as anyone else. I feel sadness, joy, hunger, love, compassion, and pain."

For me as Rick's mom, I spent this very past Monday begging the Department of Mental Health in Massachusetts to help us build an adaptive seat for Rick. He is going to have to have back surgery because he is getting a lot of neck pain from using his communicator all the time. Unfortunately, he did not have the right label to get these services.

If all persons with developmental disabilities were included in our service system, I would not have to spend my life fighting. I have been doing it for 25 years. That is a long time to fight.

The individuals who fall under the umbrella term, "developmentally disabled" are not a homogeneous group in terms of service needs. I am here today representing over one million individuals who meet the definition of developmental disabilities, but whose primary impairment is not a mental one. I call your attention that the intent of the law is not being met consistently in all 50 States. To assist States to (a) assure that persons with developmental disabilities receive the care, treatment, and other services necessary to enable them to achieve their maximum potential through independence, productivity and integration into the community. The original intent of Congress in 1963 was to develop services to meet the needs of people with mental retardation. In 1970 and 1975, this intent was extended to people with other disabilities with similar service needs, and in 1978 the language was modified to assure that just persons with the most substantial disabilities received services.

Two major differences in the definition adopted in the 1978 Act are: no specific diagnostic categories or labels are used, other than mental and physical impairment; and the necessity of a substantial functional limitation in three or more areas of major life activity. In fact, most prevalence estimates suggest that one to one and one-half million of the three million people classified as developmentally disabled are persons without mental impairments.

The definition adopted nearly ten years ago has had an impact on States, but not nearly what some of us expected. Over 20 States still have a State agency which has an exclusive responsibility to persons with mental retardation. In 1985, New Jersey was the first and only State to adopt the complete Federal functional definition in State statute. The remaining States have adopted a variety of mixed categorical and functional definitions, many with a strong mental impairment overlay.

In my home State of Massachusetts, our legislators recently split the Department of Mental Health and the Department of Mental Retardation into two departments, and we are fighting an uphill battle to broaden the eligibility for services in the new Department of Mental Retardation.

Changes in the boundaries of eligibility for services which result from adoption and implementation of the current definition will in all likelihood mean that the newly-eligible people will require even more varied levels and types of supports.

This means that past patterns of service delivery will not be able to adequately accommodate these differing demands. For example, in the area of community living, the preferred model of support services for someone with substantial functional limitations without a mental impairment is the person's own home or home with a roommate and a personal attendant hired and managed by the individual, rather than placement in an eight-bed group home or other facility.

In the emerging area of supported employment, ongoing support for persons with developmental disabilities who are not mentally impaired will include a variety of services, including transportation, therapies and applied technology, rather than a job coach.

From these two illustrative examples, I trust you can see that the actual delivery of support services for the divergent population I represent today encompasses the same concepts, but far different implementation strategies than for persons with developmental disabilities and mental impairment.

This is what we urge you to require the Developmental Disabilities Councils to do more of, to assure the services required to support all persons with developmental disabilities regardless of categorical diagnoses, that they be planned, demonstrated and assured throughout our land.

We have come a long way, but we believe it is now time to reconcile Federal intent with State policy. As Dr. Elizabeth Boggs, our national expert here on developmental disabilities, stated upon New Jersey's adoption of the Federal definition into the State statute in 1985, "We have had a non-accessing population of people, specifically young adults with severe physical disabilities, who have had nowhere to go for assistance in putting it all together. These people really deserve to have an agency that can work for them."

I urge you to first reaffirm that State Councils be involved in the system reform necessary within their respective States so that each State can adopt the Federal definition in a timely manner; and second, assure that each of the States meet the intent of the law by assigning the most appropriate agencies to be responsible and accountable to provide access to the full range of support services for individuals with developmental disabilities without mental impairments.

Until that time, the promise of the Act will remain unfulfilled. Over one million citizens will continue to be more dependent than necessary on our resources and robbed of their human dignity and opportunity to contribute to community life.

Please do not let my son be one of them. If you would like to meet Rick, over on the table is a "People Magazine" article which will show you pictures of him and give you a sense of our family system.

I thank you very much for listening to me.

[The prepared statement of Mrs. Hoyt, and responses to questions submitted by Senator Harkin follow:]

THE SENATE SUBCOMMITTEE ON
THE HANDICAPPED

HEARING ON
THE REAUTHORIZATION OF THE
DEVELOPMENTAL DISABILITIES ACT OF 1984

TESTIMONY PRESENTED BY:
JUDY HOYT
HOLLAND, MASS

ON BEHALF OF:

NATIONAL SOCIETY FOR CHILDREN AND ADULTS WITH AUTISM
NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.
DIASBILITY RIGHTS EDUCATION AND DEFENSE FUND
UNITED CEREBRAL PALSY ASSOCIATIONS, INC.
NATIONAL SPINAL CORD INJURY ASSOCIATION
NATIONAL NETWORK FOR PARENT CENTERS
SPINA BIFIDA ASSOCIATION OF AMERICA
EPILEPSY FOUNDATION OF AMERICA
TOURETTE SYNDROME ASSOCIATION

April 8, 1987

U.C.P.A. Governmental Activities Office   Washington, D.C.

My name is Judy Hoyt. I am the mother of three children. I am a Governor's appointee to the Massachusetts Developmental Disabilities Council. I am speaking today on behalf of United Cerebral Palsy Associations, Inc., Epilepsy Foundation of America, and seven other national organizations on behalf of individuals with the most severe disabilities. We share a common vision of an American society that provides opportunities for school age children with severe disabilities to be educated in public schools in a way that promotes interaction with their nonhandicapped peers; for adults with severe impairments to be employed in diverse settings earning a competitive wage; and for all children and adults with severe disabilities to live at home and in their home communities enjoying the benefits of friendship and continuing personal relationships.

My remarks today will be to paint for you a portrait of an American family: my family. The portrait is typical of thousands of families across the country who have sons and daughters with substantial functional limitations as defined in the Developmental Disabilities Act.

My testimony will describe the barriers we face as families seeking adequate and appropriate supports to enable our sons and daughters to learn, live, and work in their home communities.

Please bear in mind there are millions of moms out there like me from small towns like mine. I come from Holland, Massachusetts.

My first born son has brain damage from a face presentation at birth. He can't walk, talk, or feed himself and yet has above average intelligence. Locked in his body at eight months of age, we were told he is a vegetable; put him in an institution. We said no, we love him anyway.

Rick's own description of himself is as follows: "I was about four or five years old when I knew that I could not do what my two younger brothers could.

Physically, I could not move as they could. Verbally, I could not speak. At first I felt cheated and angry. Even though my parents talked to and treated me the same as my brothers, I felt and knew I was different.

My parents would read and explain what things were to me. I could only respond by a sound which sounded the same all the time. The physical condition I have was caused during the birth process. It has affected the cerebellum part of my brain (the part that controls the muscles). When people realize I can respond by using my mechanical communicator called a TIC, they are most surprised. I understand all things said to me. Being a non-vocal person does not make one any less of a human being. I have the same feelings as anyone else. I feel sadness, joy, hunger, love, compassion, and pain. I have many friends who are super to me. I try to be good to them also. I have one very special friend, Kevin. He helps me to feel like an able-bodied person. He hangs around with me at home, at school, and takes me all over with him. Sometimes we fight, but we don't stay mad long. We even throw a few punches once in a while at one another. I'm involved in programs for the advancement of the handicapped person. I like to think that maybe my disability and my dealing with it will help people with disabilities to be better understood. I also hope to change people's attitudes about persons with disabilities."

Monday of this very week I spent begging the Department of Mental Health facility in Massachusetts to help us with an adaptive seat for Rick. Unfortunately, he did not have the right label to get these services. If we involved all persons with developmental disabilities in our service system, this would not be the case.

The individuals who fall under the umbrella term "developmentally disabled" are not a homogeneous group in terms of service needs.

I am here today representing over one million individuals who meet the definition of developmental disabilities but whose primary impairment is not a mental one. I call to your attention that the intent of the law is not being met consistently in all 50 states...."to assist states to (A) assure that persons with developmental disabilities receive the care, treatment, and other services necessary to enable them to achieve their maximum potential through independence, productivity, and integration into the community..." The original intent of Congress in 1963 was to develop services to meet the needs of people with mental retardation. In 1970 and 1975, this intent was extended to people with other disabilities with similar service needs. And in 1978, the language was modified to assure that just persons with the most substantial disabilities received services.

The federal definition was purely categorical in 1970 (P.L. 91-517) and later evolved to a mixed categorical and functional one in 1975 (P.L. 94-103) which still had a reference to mental retardation..."results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons." In 1976, the Secretary of H.E.W. awarded a contract and appointed a task force to study the confusion and different interpretations in operationalizing the mixed definition. The task force recommended a functional approach to the definition--a non categorical definition which emphasized the complexity, pervasiveness, and substantiality of the disability condition(s). The proposed definition was included in the 1978 Act (P.L. 95-602) and continues today. The major differences in this definition from the 1975 Act are:

- o No specific diagnostic categories or labels are used other than "mental and physical impairment";
- o The age limit for onset of the disability was raised from 18 to 22;

and

- The necessity of a substantial functional limitation in three or more areas of major life activity.

Impact of Current Definition:

The current definition excludes persons with mild disabilities, and, by eliminating categories makes it possible for persons with a wide range of diagnostic labels such as spina bifida, spinal cord injury, muscular dystrophy, multiple sclerosis, cystic fibrosis, Tourette Syndrome, and others to be included in the definition along with many persons from the more traditional diagnostic categories of mental retardation, cerebral palsy, epilepsy, and autism, including many persons with multiple mental and physical impairments. In fact, most prevalence estimates suggest that 1 to 1 1/2 million of the three million people classified as "developmentally disabled" are persons without mental impairments.

Though the disabilities are different, the common elements are that the origin of their disability was in the develomental period, that the individuals will need on-going—possibly lifelong—support services and that the goal of these services should be to increase independence, productivity, and community integration as stated in the 1984 Act (P.L. 98-527).

The definition adopted nearly ten years ago has had an impact on states but not nearly what some of us expected. Over 20 states still have a state agency which has an exclusive responsibility to persons with mental retardation.

In 1985, New Jersey was the first and only state to adopt the complete federal functional definition in state statute. The remaining states have adopted a variety of mixed categorical and functional definitions, many with a strong mental impairment overlay. In my home state of Massachusetts, the legislature recently split the Department of Mental Health and the Department of Mental Retardation into two departments, and we are fighting an uphill battle to broaden the eligibility for services in the new Department of Mental Retardation.

For more than eighty years, professionals have used an approach that focuses on individual deficits as the means of deciding whether a person was eligible for available services. The functional nature of the developmental disabilities definition should force a change in determining eligibility to a focus on the interaction between a person and his/her. environment rather than focusing on deficits seen to be in the person.

Changing Service Patterns:

Changes in the boundaries of eligibility for services which result from adoption and implementation of the current definition will, in all likelihood, mean that the "newly eligible" people will require even more varied levels and types of supports. This means that past patterns of service delivery will not be able to adequately accommodate these differing demands. New service patterns will have to be developed, some old patterns abandoned, and agencies will of necessity learn to become more flexible in their dealing with individuals receiving services.

For example, in the area of community living, the preferred model of support service for someone with substantial functional limitations without a mental impairment is the person's own home or home with a roommate and a personal attendant hired and managed by the individual rather than placement in an "eight-bed" group home or other facility.

In the emerging area of supported employment, ongoing support for persons with developmental disabilities who are not mentally impaired will include a variety of services including transportation, physical, speech, and occupational therapies, medications, and applied technology rather than a job coach.

From these two illustrative examples, I trust you can see that the actual delivery of support services for the divergent population I represent today encompasses the same concepts but far different implementation strategies than for persons with developmental disabilities and mental impairment. This is what we urge you to require the Developmental Disabilities Councils to do more of--to assure the services required to support all persons with developmental disabilities, regardless of categorical diagnosis, bé planned, demonstrated, and assured throughout the land.

Conclusion:

We have come a long way, but we believe it is now time to reconcile federal intent with state policy. As Dr. Elizabeth Boggs, a national expert on developmental disabilities, stated upon New Jersey's adoption of the federal definition into state statute in 1985, "We have had a non-accessing population of people--specifically, young adults with severe physical disabilities--who have had nowhere to go for assistance in putting it all together. These people really deserve to have an agency that can work for them..."

I urge you to: 1) reaffirm that State Councils be involved in the system reform necessary within their respective states so that each state adopt the federal definition in a timely manner and 2) assure that each of the states meet the intent of the law by assigning the most appropriate agencies to be responsible and accountable to provide access to the full range of support services for individuals with developmental disabilities without mental impairments. Until that time, the promise of the Act will remain unfulfilled. Over one million citizens will continue to be more dependent than necessary on our resources and robbed of their human dignity and opportunity to contribute to community life.

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United States Senate
COMMITTEE ON LABOR AND
HUMAN RESOURCES
WASHINGTON, DC 20510-6300

April 10, 1987

Judy Hoyt
Mashapaug Road
Holland, Massachusetts 01550

Dear Judy,

Thank you for testifying before the Subcommittee on the Handicapped regarding the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. It was a pleasure to have you as a witness. Your testimony was very informative.

There are a number of questions to which my colleagues on the Subcommittee and I would appreciate your response. Please provide me with your comments on the following:

1. It has been almost ten years since the definition of Developmental Disabilities has had a functional focus. Why is it taking so long for states to change their state definitions to be consistent with the federal definition? Do you feel states will make this change in definition and service eligibility without a federal mandate?

2. Is there a single answer for all states on how to assign agencies responsibility for addressing the needs of persons with developmental disabilities who do not have cognitive impairments?

3. What do you feel are the most important issues that the Congress should address in its reauthorization of the Developmental Disabilities Act?

4. Please comment on the Administration's proposal for a new priority of Family Support Services and how it might be beneficial to you.

5. How do you feel Congress can best address the needs of individuals with developmental disabilities who are becoming older adults?

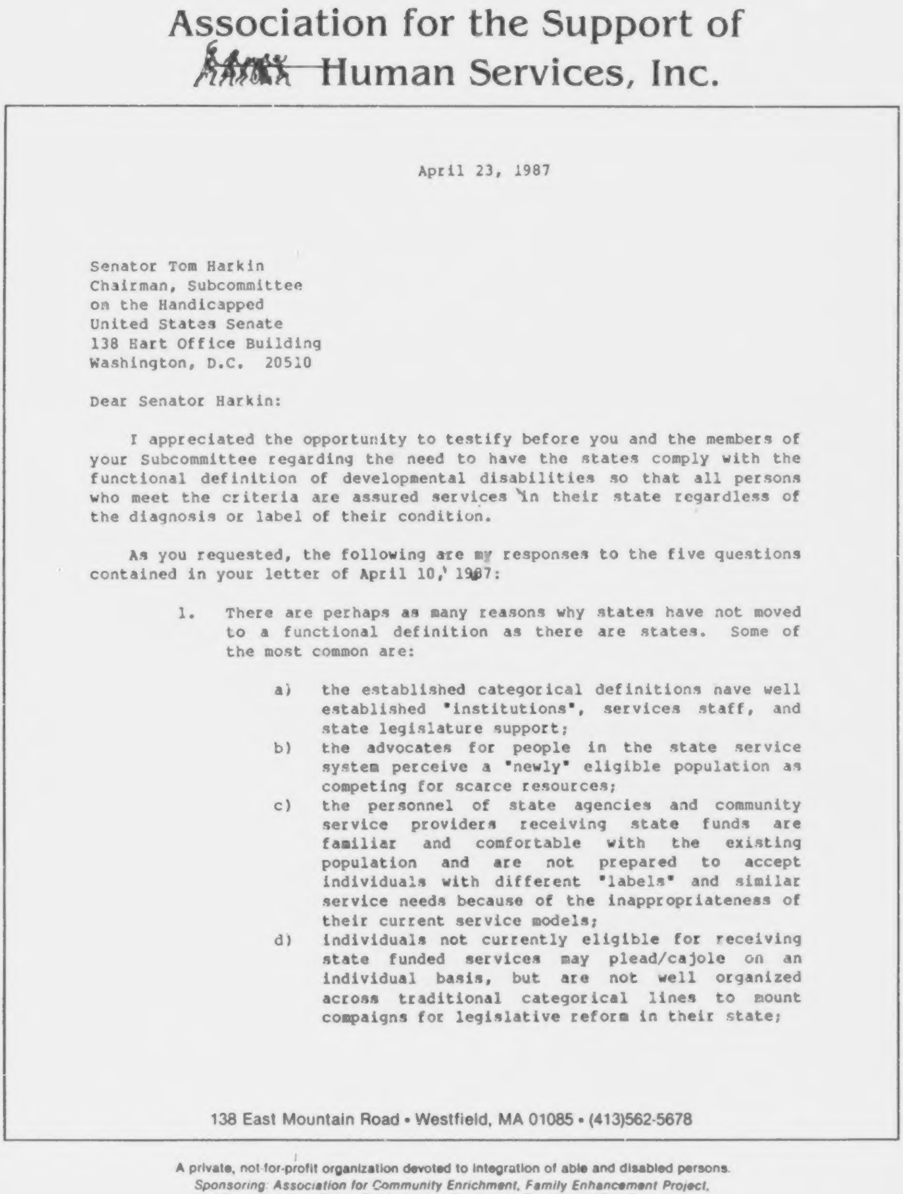
I look forward to receiving your responses to these questions and thank you in advance for your continued assistance to us as we consider the Developmental Disabilities Assistance and Bill of Rights Act. Please provide me with your written comments by April 23, 1987 when the record of the hearing will be closed.

Sincerely,

Tom Harkin

Tom Harkin
Chairman, Subcommittee
on the Handicapped

cc: Allan Bergman
TH/kb



Association for the Support of
Human Services, Inc.

April 23, 1987

Senator Tom Harkin
Chairman, Subcommittee
on the Handicapped
United States Senate
138 Hart Office Building
Washington, D.C. 20510

Dear Senator Harkin:

I appreciated the opportunity to testify before you and the members of your Subcommittee regarding the need to have the states comply with the functional definition of developmental disabilities so that all persons who meet the criteria are assured services in their state regardless of the diagnosis or label of their condition.

As you requested, the following are my responses to the five questions contained in your letter of April 10, 1987:

1. There are perhaps as many reasons why states have not moved to a functional definition as there are states. Some of the most common are:
    a) the established categorical definitions have well established "institutions", services staff, and state legislature support;
    b) the advocates for people in the state service system perceive a "newly" eligible population as competing for scarce resources;
    c) the personnel of state agencies and community service providers receiving state funds are familiar and comfortable with the existing population and are not prepared to accept individuals with different "labels" and similar service needs because of the inappropriateness of their current service models;
    d) individuals not currently eligible for receiving state funded services may plead/cajole on an individual basis, but are not well organized across traditional categorical lines to mount compaigns for legislative reform in their state;

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- e) the state Council's administering agency is potentially in "conflict of interest" with the Council's advocacy role;
- f) the members of the Council are frequently appointed by the Governor upon the recommendation of the administering agency; and
- g) the consumer members on the Council do not always represent all of the diverse needs of people with developmental disabilities in an equitable composition.

Based on nearly ten years of experience in the states, it does not appear likely that the states will adopt service assurances for all persons with developmental disabilities without a federal mandate. In addition, I recommend that states not be allowed to receive federal funds for the basic state grant program beyond a certain date in the next several years unless they agree to support one or more state agencies as a "home in government" for all persons with developmental disabilities.

2. There is no single answer and it is unrealistic to attempt to formulate one 'solution for all states re: which agency(ies) should be responsible for addressing the needs of persons with developmental disabilities who do not have cognitive impairments. A more realistic approach is to recognize the different histories and current contexts in each state by requiring the Council's to complete a policy analysis of all state statutes impacting on persons with disabilities, to review the performance of all such agencies, to obtain consumer, parent, and provider input through public hearings and to formulate recommendations to the Governor and the state legislature with a time frame for implementation no later than September 30, 1990.

3. The important issues to address in the reauthorization of the Developmental Disabilities Act are:

    - a) assurances of compliance for the reconciliation of state policy with Congressional intent regarding services in each state to meet the diverse needs of the entire population of individuals with developmental disabilities;
    - b) clarification of terminology and language to reflect current best practice regarding the strengths of individuals with developmental disabilities and the supports necessary to live, work, and play in the community as recommended by the gentleman at the hearing who was representing the Connecticut Council on Developmental Disabilities; and

c) the maintenance of employment as a mandated priority.

4. I am pleased to see the administration put forth a priority for Family Support Services. We, the family, are the bottom line; and the primary caregivers for all of our children. With appropriate support services based on each family's unique circumstances, we can raise our sons/daughters with disabilities at home and can function as a healthy, nurturing unit that develops our child and then lets go. All children, regardless of severity of disability, have a right and a need to grow up in a family.

   This priority, however, should remain a state option since over 20 states now have established either pilot or ongoing family support services. Lastly, this priority already exists within the priority of community living arrangements which should be expanded for clarification and direction, especially to the states which have not yet began this critical and most cost-effective service.

5. The current attention to persons with developmental disabilities who are getting older is a potential trap for a whole new series of specialized, segregated programs and facilities. Great attention should be paid to assuring that older Americans who happen to have developmental disabilities are afforded equal access to existing federal programs for all other older Americans with particular attention to housing, transportation, health, medical, and social needs. It will be beneficial to do some cross discipline training between gerontology and developmental disabilities.

Thank you for the opportunity to share my beliefs with you and the members of your Subcommittee. Please do not hesitate to contact me if I can be of further assistance.

Sincerely,

Judy Hoyt

Judy Hoyt

JH/cc

cc: Allan Bergman

Senator HARKIN. Thank you very much.

Dr. Boggs?

Dr. BOGGS. Thank you. My name is Elizabeth Boggs, and I am delighted again to be meeting with this Committee, which has done so much for so many people with disabilities through this and other legislation.

I appear here on behalf of the Consortium for Citizens with Developmental Disabilities, and I think you are quite familiar with the work of the Consortium, and I know its initial recommendations were made available to the Committee some days ago, as well as the testimony, which I hope will be entered in the record in the usual way.

I come to you as a member of the New Jersey Developmental Disabilities Council. I serve on that Council as a parent. As a matter of fact, I fulfill the requirement that there be a parent of an institutionalized developmentally disabled person. My 42 year-old son is one of the people who are often still overlooked.

One of the purposes of the Developmental Disabilities Act has been to be a bottom-up program, a zero reject program. And there are still some people—and you have heard about some of them from some of the other witnesses—whose disabilities are so complex and so great that the system prefers not to see them. And certainly, they do not appear before you as self-advocates at hearings like this.

I am also a member of the Board of United Cerebral Palsy of New Jersey, and I will have something to say about that in a moment; I serve on the Governmental Affairs Committee that is chaired by Mrs. Everitt for the Arcus. I was one of the architects of the original Act, and I am a veteran of the struggles to determine the definition.

Senator HARKIN. My notes tell me you are known as the "mother of the DD Act."

Dr. BOGGS. Well, all right. But I also served on that panel on the definition of "developmental disability" in 1977-78, and I am very happy that we are now working with a noncategorical, functional definition that seems to be workable enough for the work of the Councils. I am not quite sure that it is an appropriate definition to be established verbatim by all States. The concepts can be operationalized in different ways. And as a matter of fact, we in New Jersey did not quite adopt the exact Federal definition, either.

I would like to bring to your attention something that perhaps cannot go in the record. I hope that perhaps copies have already been made available to you of the article that appeared in New Jersey Section of the Sunday New York Times this past Sunday (April 5, 1987). This is an interesting article. It was secured by United Cerebral Palsy of New Jersey and is illustrated by pictures of a couple of their clients who are being served with State developmental disabilities money under two different projects. One is Project HIRE, which is a supported employment (and hopefully an unsupported) employment project, and a rehab engineering project, that enables people to have very simple devices which help them to do what they need to do prescriptively in order to hold jobs or do other things.

This article illustrates several points. The first client who is mentioned, but not depicted in that article, whose name is Darlene LaRue, lives in a group home. She is also mentally retarded as well as having cerebral palsy. She lives in a group home in my county (Hunterdon). She is active in our self-advocacy association, and she once resided in an institution.

Her story indicates, as some of the other witnesses have indicated, that we are dealing not only with a heterogeneous population—and I entirely concur with Mrs. Hoyt on that—but also a population that has all kinds of mixes and combinations of impairments. My son happens to have all seven of them.

I am pleased that this article illustrates the State Division of Developmental Disabilities at work, and I am pleased also to be able to tell you that the Developmental Disabilities Council in New Jersey worked for quite a long time—did the policy analysis that was necessary, drafted the legislation—over five or six years—to achieve the point at which the legislation was ready and the state Administration also was ready and willing to move on that particular idea of broadening the mission of the former Division of Mental Retardation.

I also would agree with what I understand to be Mrs. Hoyt's position, and that is that "the way to go" is not necessarily always by adding the non-MR populations to the responsibility of the MR agencies. That is not necessarily the only way to go. I think each State has to decide these things for themselves, and that is why policy analysis at the State level is so important, and we have emphasized that in our written testimony.

And while I am speaking of policy analysis, I would like to call your attention to something that I think has been distributed in a kit to all of the members. This is a study that was done under the auspices of the Minnesota DD Council, and it is called "A New Way of Thinking", and I think a new way of thinking is what we are interested in, and that the Councils should be on the leading edge of the new ways of thinking.

I mention that particularly because I believe that the efforts that have been made in the past to dictate priorities for the Councils and to dictate rather closely the ways that they conduct their business may be self-defeating in the long run, particularly in this era of change.

In particular, I would like to talk about priorities for a moment. There is discussion of the priorities in the Consortium document, and you will notice that some additional tinkering with priorities is suggested, and Dr. Elder made some additional suggestions, also.

I think it is very important to recognize that as far as Councils are concerned, priorities are of two kinds. There are priorities for Council action, for Council influence, for Council advocacy. You may call those in-kind-funded priorities. And then there are the priorities for spending the two-thirds of the Councils' money that are mandated to be put into something related to the specified service outcomes. And it is the argument about that latter group that has created some confusion.

I will tell you that my interpretation historically is that those priority requirements were put into the 1978 Act more for the convenience of the Congress and the Administration than out of any sense of what was really necessary at the State level. The Administration found it difficult to report to the Congress what the Councils were doing, because the Councils were using their own language and their own descriptors to describe what each had found in its unique State to be the most important things for it to do; it was thus impossible for ADD to formulate statistics and to measure global national outcomes based on these descriptions. And it was really out of that sense of frustration that the Congress, and the Senate in particular, said "We have really got to have some categories here. We want Councils to talk about what they do under headings such as employment, community services, and case management" and so forth. The Councils have been able to accommodate to this requirement by identifying what they needed to do, and then identifying it with one or another statutory classification.

But I can tell you that, in my opinion, at this stage in the game, that requirement leads to game-playing that is not really as productive as we would like and could stand in the way of the leading edge type of approach, the type of approach you just saw in the presentation from Connecticut. That was language that is nowhere in the DD Act, and yet it is precisely the kind of thing we would like to see done—the positive futures planning for individuals.

So I would urge that we talk about things that the Councils may and should be advised to attend to. Family support systems are certainly very important. However, I think when Dr. Elder points out that 20 States have already moved ahead with their own State money to support families, it is not exactly the highest priority for a Council to get in on the caboose of that movement in those States. To mandate family support as a priority for Council funding in those States is an inappropriate approach. That reminds me that I am told that the OMB talks about our program as "decimal dust", meaning that it is so inconsequential; if you have two-point-something-or-other billions, we are so far off the end of line at zero, zero, zero after the decimal point that we are considered dust; we are rounding errors in the budget process.

I think you, Mr. Chairman, correctly stated in your opening remarks that influence is the important thing. And it is fine-tuning that we are recommending here in a program that basically is very sound, thanks to the work you all have done in the past; that fine-tuning is related to keeping us up-to-date and helping us be future-oriented and not to be stagnating with some concepts that were fine four, five or six years ago and may be not on the leading edge in many States right now.

Finally, I would like to say that I do concur with the notion that we need to give more attention to equity among sub-populations, and the sub-populations can be defined in various ways. They can be defined in terms of age. For example, at the present time, the majority of people identified as developmentally disabled are between the ages of 22 and 39. But we know that sometime in the future, we will have an increase in the elderly population. The UAFs, for example, have sought to pay some attention to that and help us to prepare for the future when there will be considerably more people proportionately who are developmentally disabled in the aging population.

Finally, one of the main underlying thrusts of the original legislation in 1970 was to recognize the primary role of States. Today, States still put up more of the dollars than the Federal Government does, even when you take into account all of the income maintenance and all of the medicaid. And it is extremely important that we stand up to that and reinforce the uniqueness of the States. I want to speak particularly of the recommendation that there should be one UAF in every State. We should move toward a process where we will begin to have a prospect of having one UAF in every State.

Senator Stafford was very influential in bringing about the satellite program, and I think the satellite in Vermont has justified its existence. The satellite is the way of initiating a UAF so that it can eventually "fly up" or "fly out" and become a full UAF.

There is no doubt in my mind that the past criticism that the UAFs were ivory towers is related to the fact that "real life" is in the State system. UAFs need to have state-wide meaning so that they can respond to the State agencies, the various State agencies, necessarily just the State administering agency. A State that does not have that opportunity within its borders, is I think, deprived.

I thank you.

[The prepared statement of Dr. Boggs and responses to questions submitted by Senator Harkin follow:]

TESTIMONY RESPECTFULLY SUBMITTED

TO THE

SENATE SUBCOMMITTEE ON THE HANDICAPPED

OF THE

SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES

ON BEHALF OF

THE CONSORTIUM FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES

IN SUPPORT OF

THE REAUTHORIZATION

OF THE

DEVELOPMENTAL DISABILITIES ASSISTANCE

AND

BILL OF RIGHTS ACT

Witness:

Elizabeth M. Boggs, PhD

My name is Elizabeth Boggs and it is my pleasure to testify on behalf of the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. I have had many years of close association with the concept of developmental disabilities and with the four programs authorized by the Act. I have served on the New Jersey Developmental Disabilities Council from its inception. I chaired the first National Council on Developmental Disabilities and more recently chaired the Task Force on the University Affiliated Programs constituted by the Office of Human Development Services. The Basic State Grant Program, the Protection and Advocacy System, the University Affiliated Programs and Projects of National Significance are critical elements in the creation of a comprehensive array of services for those in our country with the severest disabilities.

Introduction

In the late sixties, a small group of national organizations interested in meeting the needs of people with severe, chronic disabilities of early life were the moving force behind the first Developmental Disabilities Act. This group, which became the Consortium for Citizens with Developmental Disabilities (CCDD), now consists of more than fifty national organizations representing people with disabilities and their families, professionals, service providers, advocates and state government agencies. The CCDD works for the improvement of federal programs across a broad spectrum of needs. Half of these organizations represent people with chronic, severe, life-long disabilities and have specific interest in the reauthorization of the Developmental Disabilities Act. These twenty-five groups have developed a comprehensive set of recommendations to improve the four Developmental Disabilities Programs for the consideration of the subcommittee.

The recommendations offered by the CCDD Task Force on Developmental Disabilities are made in the context of overall satisfaction with the current law. The reauthorization in 1984 (PL 98-527) made substantial changes in the Act which have lent themselves well to extension. The areas in need of change reflect new thinking in the field to help take us into the future. One of the strengths of the Developmental Disabilities Act has always been that it has stayed ahead of the times, it expressed new trends and pointed the way to emerging issues, staying on the cutting edge and in the vanguard of "consumerism" in the DD field. Most of all, we seek to fine-tune and strengthen already effective programs so they can be even more effective. Attached to this testimony is a document containing the specific recommendations of the CCDD Task Force on Developmental Disabilities which we hope will be helpful to the subcommittee in its deliberations. My testimony will attempt to summarize this document.

Reflecting Best Practices and Anticipating the Future

During the 1984 reauthorization process, the purposes of the Developmental Disabilities Act were refined and expanded to include "increasing the independence, productivity and integration into the community of people with developmental disabilities." In the three years' experience operating under these expanded purposes, attention has been focused more clearly on the capabilities as well as needs of people with developmental disabilities. As more and more people are able to live in their own home or return to their community, there is an ever increasing need to provide individuals and families with the wherewithal to maintain that independence.

The CCDD seeks to amplify the purpose statement of the Act to state clearly that the programs also have as their intent the empowerment of individuals and families to live life more fully; that is, to provide the context within which people with developmental disabilities and their families can exercise their rights, benefit from the freedoms, and undertake the responsibilities of citizenship in their communities!

CCDD offers some suggestions to fine-tune and keep current the general provisions and definitions in Part A of the Act. The current federal priority areas (alternative community living arrangements, child development services, case management and employment-related activities) are meeting well the planning and advocacy functions of the Basic State Program. However, the terms themselves do not suggest concrete outcomes for people. Therefore we are recommending that "alternative community living arrangements" be changed to "community living" - our main goal for people with developmental disabilities. We also recommend that "child development services" be changed simply to child development - our positive goal for children. And lastly, that "employment-related activities" be changed to "employment" - the outcome we seek for all adults.

The CCDD believes that by restating the priority areas, the law will signal the intention of these programs to achieve measurable outcomes for people with developmental disabilities.

In the field of developmental disabilities, things change rapidly. Because Developmental Disabilities Councils, Protection and Advocacy Systems and University Affiliated Programs have emphasized employment since 1984, there has been a broader investigation into the needs of adults with developmental disabilities, resulting in an awareness of the critical need to develop state-wide systems of case management. After studying the state of case management in the states, changes in its definition are needed which stress the inter-agency monitoring of services and the advocacy role of the case manager to gain increased access to services for individuals. The critical role of DD Councils during the next three-year period should be to help shape the design of multi-level systems that work for individuals as they are served within particular provider agencies, to ensure inter-agency coordination, and to communicate gaps in services to those in policy-making positions in the state.

The CCDD recommends new language for the definition of case management.

Similarly, we would like to see "applied technology" be added to the kinds of activities which can be addressed under both the employment and community living priority areas. This recommendation is consistent with our desire to provide supports to individuals in the community which enable them to lead productive lives.

We offer a definition of "applied technology" to be added to Section 102.

While there is great satisfaction with the current federal priority areas, there are many activities which do not fit into these categories. Often, activities address both residential and employment needs, or focus on urban or rural services across all priority areas. Also, activities which help to undergird states' efforts on behalf of the priority areas, such as socio-legal services, information and referral, outreach, community acceptance and public education, etc., sometimes do not "fit" into the federal priorities and yet are critical to the advocacy role of the DD Council.

Therefore, the CCDD recommends that the state optional priority be reinstated (it was inadvertently deleted during recodification in 1984) and redefined to permit such activities which would effect positive change in specialized or generic services and/or which address two or more federal priority areas.

BASIC STATE GRANT PROGRAM

More Effective Leveraging of Services

Shortly after enactment in the early 1970's, it became clear that the Basic State Grant Program was not to become a federally financed service system for people with developmental disabilities. The dollars simply were not there. Congress redirected the program to one of advocating for and leveraging other sources of funds and the program has been exceedingly successful in doing this nationwide. However, there is still language which permits the provision of direct services with these limited dollars and frequently, in states where the Councils do not have the autonomy they need for advocacy within state government, funds are used to finance services that should be paid from other sources.

Thus, CCDD wants Congress to ensure that any direct services provided under Part B are for the purposes of demonstrating the efficacy of a service for the short-term and that such demonstrations be linked to strategies for continuation with other funds. Our recommendations contain language to achieve that result.

Also, activities which change state policies have been among the greatest success stories of the Basic State Grant Program. Analyses of the impact of state policies can be used to convince and educate state policy makers of the need to improve services to people with developmental disabilities.

Policy analysis and educating policy makers are related activities which need to be clearly added to the list of ways priority areas can be addressed.

The DD Councils are at various levels of sophistication in the design of and advocacy for services to persons with developmental disabilities. We are learning at an accelerated pace in our field about how to provide support in the community to people with severe disabilities. The state of the art is evolving rapidly and some Councils are way ahead of others. This brings with it a suggestion that Congress express its intent that Councils evaluate services against professionally accepted best practices.

Strengthening State-wide Planning and Advocacy

The CCDD has suggestions for State Plans developed under the Basic State Grant Program which provide DD Councils with additional flexibility to address their most critical needs and to strengthen the ability of DD Councils to advocate effectively within their states and territories. The four federal priority areas have served the Councils well during the last three years and continue to be applicable for planning and advocacy purposes. At present, Councils are limited in their selection of priority areas - they can only select three and one of them must be employment. This limitation prevents them from clearly describing many cross-cutting and inter-agency initiatves in a precise way. The mandate to select employment served an initial function to get all Councils involved in this area. State Councils themselves, in fact, advocated for the addition of employment, having found non-vocational social developmental services (the previous priority area) too limited a term. Forty-three Councils selected employment in FY 1986 - before the mandate in FY 1987. We have made available to subcommittee staff an impressive listing of the activities funded under this priority. Since all Councils have now embarked upon long-range capacity building activities in this area, it is no longer necessary to require such selection.

The CCDD recommends that Councils be permitted to select up to four federal priority areas and that the requirement to select employment be lifted.

As mentioned above, the need for an ability to select additional activities which do not fit into the federal priorities should be addressed by reinstating the state optional priority.

The state plan should describe the state option and include an assurance that it is essential to the development of a comprehensive array of services for people with developmental disabilities.

In 1984, DD Councils were mandated to receive annual survey reports of plans of correction for cited deficiencies in their states' intermediate care facilities for the mentally retarded/developmentally disabled (ICF/MR/DD).

The CCDD would like to see the law go beyond simple receipt of these reports and require Councils in their Annual Reports to describe what states have done to address problems raised by these reports and, further, what the Council response was.

Finally, the CCDD recommends that the State Plan indicate what resources exist in the states and terriroties to meet the needs of people with developmental disabiliites who do not have cognitive impairments.

Strengthening DD Councils

DD Councils have greatly increased in sophistication in the last three to five years. They have shown remarkable ingenuity in using limited DD dollars to leverage other funds and services. There are still, however, some Councils which are thwarted in their attempts to direct the expenditure of funds for the building of the capacity of the system of services. The major barrier to successful advocacy has been untoward control of some Councils' decisions and implementation activities by the designated administering agency. The CCDD feels that this situation must be remedied. Because the relationship of the Council and Administering Agency has never been clearly specified during the history of the program, there are many different arrangements which have developed on the state level - most of which are highly succesful. Some, unfortunately, are not. We do not wish to require that Councils be placed in any particular place within state government, since over the years many excellent administrative arrangements have evolved in the states; however, it should be clear that the Council reports directly to the governor wherever it is placed. Also, there is antiquated language in the law which refers to the "administering agency" or "agencies," language left over from previous amendments in which funds were parcelled out to state agencies which "implemented" the state plan.

The CCDD recommends that the law specify that there is a single state agency to administer the program and that the DD Council be permitted to be its own administering agency. The Consortium further suggests that the law clarify that the Council should be organizationally located with appropriate stature and resources within the state system to advocate effectively for people with developmental disabilities and should report directly to the governor.

A related problem concerns staff to the Council who are technically paid by the administering agency - thereby working for "two masters". In many states it is difficult for the Council staff to implement directives of the Council because of policies of the administering agency. Federal executive branch policy issuances have attempted to solve this problem; however, they have been unsuccessful in correcting the situation in some states.

The CCDD recommends that the statute firmly state that Council staff are not to be assigned duties by the administering agency and that the Council must supervise and direct the activities of its staff. There also needs to be an assurance that staff is in sufficient quantity to enable the Council to carry out its duties under the statute.

Resources

In the funding area, we have several recommendations relating to the Basic State Grant Program.

DD Councils need to be able to carry over 10% of their yearly allotments to avoid year-end problems of reobligation of funds which are returned by subgrantees in the next fiscal year. We also recommend that ADD have the ability to increase the minimum allocations administratively in those years in which appropriations are greater than the CPI rate of increase. The minimum state allotments should be increased to $350,000 and territories to $200,000. Finally, we recommend that appropriations be authorized for the Basic State Grant Program at $62.2 million for fiscal year 1988, $69.9 million for fiscal year 1989, and $77.4 million for fiscal year 1990.

PROTECTION AND ADVOCACY SYSTEM

Introduction

The year 1987 marks the 10th anniversary of the Protection and Advocacy System for People with Developmental Disabilities. The P&A System has grown from its early years in funding levels, authority, and experience. The P&A ststem has grown from an initial funding level of $2.5 million in FY 1976 to $15.5 million in FY 1987; however, the broad mandate created by the legislation in 1975 has not yet been fully realized, and the service needs of persons with developmental disabilities still require expansion of aggressive advocacy services.

In fiscal year 1986, Protection and Advocacy agencies provided direct services to 50,000 people. In addition, thousands of persons benefitted from systemic action initiated by the Protection and Advocacy System. These figures do not include the thousands of people with disabilities who received information and referral services from the P&A system as well.

An indication of the success of the P&A system in promoting the independence of people with developmental disabilities is the fact that over 80 percent of the cases in which the system intervened in fiscal year 1986 were resolved satisfactorily.

With the passage of the Protection and Advocacy for Mentally Ill Individuals Act of 1986, Congress reaffirmed its commitment to the P&A model by extending these servies to individuals labeled mentally ill throughout the country. That Act provided $10 million for each of three years to protect and advocate for persons who are labeled mentally ill and reside in facilities providing care and treatment.

The P&A system has demonstrated it effectiveness in its first decade of operation and is anxious to reach its full potential in the second decade. It will do so only with adequate resources with which to address all those in need.

Following are the recommendations for the Developmental Disabilities Assistance and Bill of Rights Act of 1987 which concern the protection and advocacy of individual rights.

Aligning the P&A Purpose with the Overall Purpose of the Act

The purpose of the P&A System should closely reflect the overall purpose stated in the Act.

CCDD recommends that after the phrase, "of persons with developmental disabilities," the phrase, "to assure that they receive the services necessary to enable them to achieve their maximum potential through increased independence, productivity and integration into the community," be added.

Unmet Needs

There remain, however, many unmet needs. And the P&A system has been forced to set priorities for services. The problems of people with developmental disabilities inappropriately placed in nursing homes is one of a number of critical issues facing the P&A system. Many people have been placed on waiting lists, often the very problem the individual wished the P&A to address in the service system. Other problems include: the needs of minorities with developmental disabilities; the needs of people with developmental disabilities who come into contact with the criminal justice system; and the needs of children for the least restrictive educational setting.

Minority persons who have developmental disabilities have been a priority for service for many Protection and Advocacy agencies. The Department of Health and Human Services has provided funds in the past for P&As to develop outreach programs through demonstration grants from the Office of Civil Rights and the Administration on Developmental Disabilities.

It is strongly suggested that a specific focus be added to the Act to meet the needs of underserved minority persons.

Protection and Advocacy agencies, because of insufficient resources, have not adequately addressed the needs of persons with developmental disabilities who become involved in the criminal justice system.

The CCDD supports the addition to the Act of a specific focus addressing the needs of persons with developmental disabilities involved in the criminal justice system.

The P&A agencies have been heavily involved in the enforcement of P.L. 94-142, the Education for All Handicapped Children Act. P&As report that 40% of their cases involved special education issues. This effort must be further enhanced.

The CCDD strongly supports providing to the P&A system in each state and territory the reports from the Office of Special Education at the U.S. Department of Education and the state monitoring reports of local education agencies.

Strengthening the Protection and Advocacy System

Because individual problems frequently require overcoming local and state policy barriers, the P&As must be able to advocate for persons with developmental disabilities before all appropriate governmental entities such as boards, commissioners, city and county councils and state legislatures.

Specific language should be included in the P&A authority to make clear that the P&A systems may advocate before appropriate public bodies on behalf of the people they serve.

The Protection and Advocacy system engages in a priority setting process at least every three years and many agencies review priorities annually. Community input would enhance the process and assure accountability of the system.

Specific provision for input by the disability community should be included in the planning and priority setting activities of the Protection and Advocacy System.

Protection and Advocacy agencies, like any other service provider, should be accountable to the people they serve. At times individuals may be dissatisfied with the handling of their case and should be afforded the opportunity to challenge the decision of the Protection and Advocacy system regarding their case. Recognition should be made, however, of the extensive P&A mandate, the limited resources available to carry out this mandate and the impact this limitation poses regarding responding to such complaints.

CCDD recommends a provision for a client grievance procedure within the P&A authority to assure that people with developmental disabilities have full access to advocacy services.

Based on the continued depopulation of state institutions and nursing homes as well as the relocation of individuals within community living arrangements, a large number of individuals are being moved with no advocacy or legal representation.

Language is strongly suggested to provide the P&A system with standing and representation in all situations where an individual over the age of 18, without a family or legal guardian other than the state or county (which have a potential conflict of interest), who is being considered for a change in his or her living arrangement, to assure that the proposed new arrangement is appropriate to the individual's needs and that the services needed are in place or will be in place prior to such a move.

Several P&As use subcontractors to achieve a full range of advocacy services throughout the state. From time to time, subcontractors will return unexpended funds in the next fiscal year, which the P&A then cannot use for recontracting of services. Use of these funds should be allowed with timelines on reobligation and liquidation.

There is strong support for an allowance for carryover of 10% of the yearly allotment to give flexibility in management and to avoid problems of obligation of funds. Additionally, funds which were obligated in the current fiscal year but are subsequently returned in the next fiscal year should be available for reobligation and should not be required to be returned to the federal government.

Resources

The minimum allotment should be readjusted to enable P&As in all states to provide an adequate level of service.

The CCDD supports the ability of the Commissioner of the Administration on Developmental Disabilities to have the option to raise minimums administratively in years in which an appropriation increase for that year is greater than the percentage increase in the Consumer Price Index.

Additionally, the minimum allotment for P&As should be raised automatically to $250,000 when appropriations reach $20 million.

Based upon increased mandates for the expanded services described above, the authorization levels for the P&As need to be increased.

Recommended authorization of appropriations for FY 1988 is $25 million: for FY 1989, $28 million and for FY 1990, $31 million.

UNIVERSITY AFFILIATED PROGRAMS

Introduction

From its inception, the network of University Affiliated Programs has had a unique mission that can be traced back to the early 1960's. The President's Panel on Mental Retardation, created in 1961, initiated the concept of training the multidisciplinary core of professionals required to deliver appropriate and needed services to people with developmental disabilities. While funds for the construction of research and training centers on university campuses across the country were initially authorized in the Mental Retardation Facilities and Community Mental Health Centers Act of 1963 (P.L. 88-164), the specific statutory mandates for the UAF network were not defined in federal law until 1978 with the passage of the Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments (P.L. 95-602). Section 102 of that legislation defined the term "university affiliated facility" as a public or nonprofit facility which is associated with, or is an integral part of, a college or university and which provides for at least the following activities: (1) interdisciplinary training for personnel concerned with developmental disabilities; (2) dissemination of findings relating to the provision of services; and (3) providing researchers and government agencies sponsoring service-related research with information on the need for further service-related research.

From these beginnings has developed an aggregation of university based programs for pre- and in-service education in the field of developmental disabilities which now constitute the most significant specific training locations in the country for this work.

Resources

In general, funding for the University Affiliated Programs has followed the broader pattern of federal government support for mental retardation and developmental disabilities training. In real economic terms, training funds advanced consistently upward every year between 1963 and 1972. Thereafter, training expenditures fell equally rapidly. Total training funding for 1985 was only one-fourth of the peak real funding level in 1972; and, along with the 1984 figure, it represented the smallest spending commitment for training in 22 years.

Why are these funding trends significant? What is the importance of having adequately trained personnel provide basic services to persons with developmental disabilities? From a policy perspective, the monies expended on badly needed services are only as effective as the availability of adequately prepared professionals qualified to administer them. In order for people with developmental disabilities to live in community settings, to work in competitive employment environments, and to participate fully in integrated classrooms, it is essential that our educators, physicians, group home workers and allied health professionals have the skills necessary to address the specialized needs of people with developmental disabilities. Service personnel must be prepared to have an informed awareness of individual needs and -- perhaps most important -- an understanding of the individual's family and community support systems.

Viewed in this light, it is clear that decreasing support for the UAP system will inevitably compromise the availability and quality of health care and other services to people with developmental disabilities. According to data published by Dr. David Braddock in a recent study entitled, "Federal

Spending for Mental Retardation and Developmental Disabilities," the Adminstration is spending -- in real terms -- one million fewer dollars on UAPs today than it did at the inception of the program in 1972 ($4.25 million in FY 1972 compared with $3.345 million in adjusted dollars as of FY 1985).

The principal impact of this reduction is to impair the UAP network's ability to "leverage" other funds. Congress envisioned a unique financing approach in establishing the UAP network. These programs use their federal monies primarily for administrative expenses, but use the all-important federal commitment to attract funds from state, local and private sources. The leveraged funds then provide the operational dollars necessary to carry out their training and exemplary services mandated by the statute. In fact, while ADD-funded UAPs received $7,653,750 in core funding during FY 1986, these same programs generated $45,211,000 from federal sources, including the Division of Maternal and Child Health, the Department of Education, and NIH. Yet all federal funding accounted for just over 25% of the total UAP resources. The small ADD investment resulted in a total income of $122,000,000 nationwide or a ratio of $16 generated for every $1 federal dollar invested. The largest sources of other funds include general university revenues and state and local support in the form of grants or contracts from governmental entities and community-based private nonprofit organizations.

But because federal support has eroded over the past decade, those dollars are making up an increasingly small share of the overall network budget. As a result, it is now more difficult to maintain the developmental disabilties focus of these programs to attract funds necessary to carry out the mandated training and exemplary service functions. It is crucial to recognize, however, that the federal commitment establishes the broader programmatic structure for the UAP network. Specifically, DD core funding provides the critical mission for the disparate resources gathered by UAFs. Without that seed money, the developmental disabilities focus of these programs may be lost or compromised. The presence of Developmental Disabilities Act funding provides the central mechanism, within sometimes vast university educational systems, to coordinate monies from many different sources towards a set of federally established objectives. From a practical perspective, deficiencies in federal support have had an impact not only on training, but on the exemplary service function of UAPs as well. The intensive, highly specialized services provided by UAPs allows many children with severe, multiple disabilities to remain in their home with their parents. However, faced with funding constraints, these programs are not able to meet the demand for service referrals made by state programs, community service agencies, schools and primary care physicians. Thus, the children are often referred to large residential facilities where care is significantly more expensive, both in dollars and in disruption to the child and family caused by out-of-home placement. Yet all current knowledge stresses the importance of supporting people in the home and building local community capacity for services.

The CCDD-recommended authorization levels begin to ameliorate some of these difficulties and they also permit UAPs to effectively address broader issues that will soon dominate the developmental disabilities landscape.

Unmet Needs of Older People Who Have Developmental Disabilities

There are over 200,000 individuals in this country who are fifty-five years of age or older who have developmental disabilities. The number of people in this age group is projected to increase to 589,000 by the year 2020. Thus, as we approach the 21st century, about 4 out of every 1000 older Americans will have a developmental disability.

Many parents have provided life-long support at home for their sons and daughters with a disability. As these parents age, they can become incapable of providing continued support for their offspring. States and communities are increasingly confronted with the task of finding appropriate community-based settings. Often, these adults with developmental disabilities are placed inappropriately in nursing homes. The CCDD recognizes that one of the first steps to providing the appropriate quality and mix of services to older Americans with developmental disabilities is adequate personnel preparation. Such training should be provided to a broad array of professionals including social workers, occupational and physical therapists, audiologists, speech pathologists, nutritionists and many other disciplines.

Consequently, CCDD supports a cross-training proposal whereby UAPs, co-located in the same or adjacent universities with gerontological training programs, provide instruction in the processes of aging and the basic competencies necessary to effectively meet the needs of elderly persons with developmental disabilities.

Infants and Toddlers

Another area with enormous personnel preparation implications involves the recently passed Education of the Handicapped Act Amendments of 1986 (P.L. 99-457), which authorized a new early intervention program for disabled infants from birth to three years of age. The program is designed to assist states to develop and implement statewide, comprehensive, coordinated, multidisciplinary, interagency programs of early intervention services for infants and toddlers with disabilities and their families. The program mandates the provision of family training and counseling, case management, physical and occupational therapy, psychological services, early identification, screening and assessment services, and many others. In passing this legislation, Congress found that properly administered early intervention services strengthen prevention, faciliate future community integration and actually reduce the severity of a child's functional limitations while improving parental involvement.

However, current data reveal a severe lack of qualified personnel in certain key disciplines to meet the expectations embodied in the EHA. For example, of the 44,000 members of the American Occupational Therapy Association, approximately 53% (or 20,000) either work with children exclusively or serve both children and adults. While this figure represents a dramatic increase in the number of occupational therapy personnel engaged in pediatric practice, it is clear that the majority of pediatric therapists are treating children ages five through 18 years of age. In fact, less than 2% of occupational therapists work primarily with children during the first year of life. In addition, it is alarming to note that similar personnel shortages are shared by the other critical allied health disciplines. A recent survey of the 50 states indicates that 96.2% report substantial shortages of qualified physical therapists, speech pathologists and occupational therapists to work in the early intervention program. Eighty-two percent of these states expect the shortage to continue through 1989.

Therefore, CCDD recommends augmenting training dollars provided under the EHA for educational professionals by establishing development and implementation projects at five to seven universities for allied profiessionals across the country. UAPs would be specifically responsible for producing a range of professionals from a variety of allied health disciplines to work exclusively in the early intervention programs once they are implemented at the state level.

Direct Care Workers and Paraprofessionals in the Community

The CCDD has long advocated for the community integration of people with developmental disabilities. The enhanced developmental progress and quality of life of people who live in natural communities and family-sized households have been amply demonstrated. A consequence of this approach is that people with developmental disabilities increasingly live, work, and recreate outside of environments with formally trained professionals.

As the community system evolves toward less restrictive, better integrated community options, the direct responsibilities given to paraprofessionals to ensure high standards of care and habilitation are increasing. The principal difficulty, however, is that we are not producing trained direct care staff in sufficient numbers or quality to meet current demand or projected needs. For example, the existing nationwide demand for paraprofessionals (i.e., psychiatric technicians, rehabilitation assistants, case-workers, house parents, job coaches and group home workers, etc.) is approximately 50,000 for community residential facilities alone. By the year 2000 that figure increases to over 75,000. Moreover, just to keep pace with the average turnover in these positions between 1987 and 2000, 34,000 new paraprofessionals per year will need to be trained.

Clearly these estimates suggest that the lack of appropriate personnel development could become a substantial road block to community integration of people with developmental disabilities. A new training initiative is needed which will organize and prepare existing state and community personnel development programs and will assemble, evaluate and quickly disseminate curriculum to the community instructional institutions doing the actual training.

Therefore, CCDD proposes a paraprofessional training initiative whereby UAPs would adminster five to ten training programs for direct care workers and paraprofessionals. In view of the substantial task ahead, this recommendation represents an immediate and cost-effective method of building training capacity at the local level.

Complete and Expand the Network of UAPs

Finally, CCDD supports the creation of a University Affiliated Program for every state and territory. Because the existing feasibility study process is under-funded, many states and territories, and in some cases substantial portions of entire regions, have no organized federally sponsored program to provide exemplary services and training in the developmental disabilities field to allied health professionals, parents and physicians already in the field.

CCDD, therefore, proposes the conduct of simultaneous expansion studies leading to the establishment of satellite centers for all states and territories by FY 1989.

SPECIAL PROJECTS

Introduction

For many years, advocacy organizations have been dissatisfied and disappointed with the overall results of special projects funded under this authority. The needs of the developmental disabilities community for nationally significant activities are greater now than ever, and, as funds for special projects have been reduced over time, less and less has been available for the kinds of activities which provide crucial information needed by state and federal policy makers to make decisions based on facts.

New Title and Purpose

The current "special projects" approach should be abandoned and the "nationally significant" aspects of this authority should be elevated to be the primary purpose of this program.

Grants and contracts authority for up to five years should be authorized for "Nationwide Policy Initiatives to Improve Services to People with Developmental Disabilities." The CCDD recommends four areas for these nationwide initiatives, each with a dollar amount earmarked.

Policy Analysis and Dissemination which are Nationally Significant

The first segment of Nationwide Policy Initiatives, funded at $1 million, should ensure the on-going collection of data to be used for policy analysis and dissemination nationwide regarding policies and services affecting people with developmental disabilities. This part should be divided into two major sections: the collection and dissemination of data regarding funding of services under various federal and state authorities and the collection and dissemination of data regarding the activities and funding priorities of DD Councils, State Developmental Disabilities Agencies, the Protection and Advocacy Systems and University Affiliated Programs, as well as the Nationwide Policy Initiatives authority.

The second segment should earmark $400,000 for the on-going development and provision of training and technical assistance to the programs authorized under the Act, including state administering agencies where appropriate.

The third segment should earmark $1 million for federal interagency initiatives which are nationally significant in increasing the capacity of states to serve people with developmental disabilities. This model has been used most effectively in the recent past and should be formalized and continued. Such cooperative projects could include the Social Security Administration, the Department of Housing and Urban Development, the Department of Labor, the Office of Special Education and Rehabilitative Services, the Health Care Financing Agency and other agencies.

The fourth segment should earmark $250,000 to explore the feasibility of a nationwide information and referral system for parents and people with disabilities, professionals and policy makers.

Congressional Control Is Needed

For the past three years, the Office of Human Development Services has co-mingled the discretionary funds from each of its constituent agencies, under the rubric "HDS Coordinated Discretionary Grants" and has designed requests for proposals which address what are called "cross-cutting" needs. This practice has resulted in the dilution of limited developmental disabilities funds, the only locus within the federal government for people with developmental disabilities, to address these special concerns. Despite Congressional objections during appropriations hearings, the practice has continued. In addition, the priorities for which funding was available have not been subject to any systematic input from the field.

The CCDD recommends that the statute strictly prohibit the co-mingling of funds under Part E with any other authority within or outside the Office of Human Development Services. Further, the ADD should be required to solicit the views of the field prior to the publication of the announcement of its priorities and should be required, through the regulatory process, to address the suggestions made regarding the expenditure of National Policy Initiative funds.

Finally, the CCDD recommends authorization of appropriations for FY 1988 at $2.65 million, for 1989 at $2.78 million and for 1990 at $2.92 million.

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United States Senate
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WASHINGTON, DC 20510-6300

April 10, 1987

Elizabeth M. Boggs, Ph.D.
Henderson Road
RD 2, Box 439
Hampton, NJ 08827

Dear Dr. Boggs,

Thank you for testifying before the Subcommittee on the Handicapped regarding the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. It was a pleasure to have you as a witness, and your testimony was informative and helpful.

There are a number of questions to which my colleagues on the Subcommittee and I would appreciate your response. Please provide me with your comments on the following:

1. In your written recommendations, you propose modifying the requirement that all states select the priority area of employment. You also state that states "can be expected to continue working in this area without a federal mandate." If employment is so critical to persons with developmental disabililities and states are expected to continue to make this a priority, why change the law? Is it possible that some will misconstrue the change as a diminution of the importance of employment?

2. Also in your written testimony, you state that funds for the Developmental Disabilities Special Projects Grants have been "commingled" with other funds from the Office of Human Development Services for what has been called "cross-cutting" needs. Since this is a very small program, it seens inappropirate to use these funds for any activity that does not directly benefit the developmentally disabled. Can you elaborate on this problem?

3. If Congress makes the changes to the "Special Projects" proposed by CCDD, what types of specific policy-oriented impact could we expect?

4. Given the recommendations by the CCDD Task Force, which do you feel are the most important?

Elizabeth M. Boggs, Ph.D.
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5. Do you feel that the annual report requirements have increased the accountability of the Developmental Disabilities Program?

6. Are advocates/providers doing enough to involve minority populations in policy development and programs for the DD population? If not, what more can be done?

7. Congress is in the process of reauthorizing the Older Americans Act. Do you have legislative recommendations with respect to older individuals with developmental disabilities?

I look forward to receiving your responses to these questions and thank you in advance for your continued assistance to us as we consider the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. Please provide me with your written comments by April 23, 1987 when the record of the hearing will be closed.

Sincerely,

Tom Harkin

Tom Harkin
Chairman, Subcommittee
on the Handicapped

cc: Susan Ames-Zierman
TH/kb

Consortium for
Citizens with
Developmental
Disabilities

April 23, 1987

The Honorable Tom Harkin
Chairman, Senate Subcommittee on the Handicapped
Committee on Labor and Human Resources
SD 428 Hart Senate Office Building
Washington, DC 20510

Dear Senator Harkin:

Thank you for your letter of April 10. I appreciated the opportunity to provide testimony on behalf of the Consortium for Citizens with Developmental Disabilities and am pleased to offer further comments at the request of the subcommittee.

1. The Elimination of the Requirement to Select Employment as a Priority Area.

In preparation for the reauthorization of the DD Act in 1984, DD Councils recommended that the former priority of "non-vocational social development" be changed to permit employment-oriented activities. Many such activities were undertaken across the country under the rubric of "non-vocational" services because there was clearly a need to fill this gap in many states (Vocational Rehabilitation agencies were finding people with developmental disabilities not meeting the definition of "employability") and the area of non-vocational social development was the closest "fit." Coincidentally, the Administration began a major national initiative to employ people with disabilities; therefore, to ensure that states took maximum advantage of the President's Employment Initiative, it was felt that this priority should be mandated. Congress rightly felt, however, that such a requirement should not start until the beginning of the next three-year planning period (FY 1987) and should be accompanied by an increase in funding to permit the selection of an additional priority. More than 40 states did in fact elect employment prior to the mandate and many of those which did not elect employment as an area in which to spend priority service dollars did, nevertheless, undertake employment-related advocacy activities. All this serves to say that many states identified employment as a high priority, given the specific needs of each state, without a mandate to do so.

It is important to understand the mechanics of priority selection and the strategic use of federal developmental disabilities funds at the state level. The strategies that are most likely to be effective in accomplishing the goals of independence, productivity and integration vary with place and time.

Depending on circumstances, the Councils may find it appropriate to designate a particular area for emphasis for as little as one year or as many as five or six. During this period and in any particular year, it may or may not be necessary to assign some or much of the Council's "service priority" dollars to this area. Timing is particularly important. Where "start-up" costs, or should be free to use the strategies it deems most appropriate at any given time, including being free to select the strategic uses of all their federal funds consistent with the purposes of the Act.

It is not a diminution of the importance of employment to say that a particular state may need to address the other three areas more urgently. In many states, there still is no comparable, state-wide community residential system, no state-wide case management linked to management information systems or comprehensive early identification and intervention services. A mandate for any one of the four priorities invalidates the planning process that so many of us have spent so long in developing and ignores the fact that needs are best identified at the state and local level.

2. Coordinated Discretionary Authority

Within the Office of Human Development Services there are five administrations: the Administration on Aging, the Administration on Children Youth and Families, the Native American Administration, Head Start and the Administration on Developmental Disabilities. The target populations are: the elderly, adoptive and foster children, Native Americans, pre-school children, and people with developmental disabilities. These programs have varying configurations at the state and local level: some are state grants with state-wide planning requirements, others are grants-in-aid to local providers. As in any organizational structure, the entities which are combined vary from administration to administration and these five groups have not necessarily been combined because of similarities in the eligible populations. For example, the Administration on Development Disabilities used to be within the Rehabilitation Services Administration, which has since been transferred to the Department of Education and paired with the Office of Special Education. While there may be "logical" or "right" ways to organize government, it does not always follow that programs so grouped are the best possible programmatic combination. Coordinating the grant giving process as an administrative convenience appears to have resulted in increased efficiency for processing grant applications. However, it has not led to the appropriate targeting of limited DD funds where they are most needed. It is obvious that the most serious problems faced by the recipients of one program are not necessarily the most serious problems faced by recipients of another program. (ie., the most serious problems faced by Native Americans are not necessarily related to developmental disabilities. Elderly people with developmental disabilities are not necessarily a higher national priority than some other subgroup. The effect of the coordinated discretionary program has been to skew national priorities to fit into a convenient bureaucratic arrangement. Also, the process, designed under previous OHDS leadership, is not conducive to funding activities deemed essential in the developmental disabilities field. The CCDD recommendations address the need for a public process to guide the expenditure of DD discretionary grant and contract funds.

There are two other problems with the "commingling" tactic. First, it is a smoke screen for overall reduction in project funds available to all the agencies within OHDS. Secondly, by requiring that all grants serve multiple purposes, ADD is inhibited from targeting funds on problems that arise primarily in the developmental disabilities field. Neither of the two major centers (at the University of Minnesota and the University of Illinois at Chicago) has been receiving significant continuing funding from ADD since demonstrations of a new modality of service are part of the strategy and direct operational costs cannot be covered from any other source, a year of planning followed by a year or two of "doing it" may suffice to launch an activity such as technical assistance in rehabilitation engineering, or, where interagency collaboration is required (as in the early intervention programs, or programs to effect transition from school to work, or special needs adoptions), the demonstration phase may have to be sustained. It is very important to withdraw developmental disabilities grant support at the right time. The right time may be when other federal funds for this purpose are on the horizon, or when the demonstration has attracted the attention of the governor, or been added to the state Medicaid plan, or state funds are provided.

A universal mandate to maintain the same priority in all states over a protracted period of time undercuts the credibility of the priority itself as well as damaging the image and autonomy of the Council. Given the option, some Councils will continue the priority; others will have good reason to shift their emphasis and thus move on to another leading edge, another "new way of thinking."

In 1978 the Councils were given a message that vocational rehabilitation and hence employment were a "no-no"; there was to be no trespassing on the territory of state vocational rehabilitation agencies. In view of the fact that such agencies are alleged to be spending close to $200 million a year on rehabilitation of people who have one or another of the conditions usually associated with developmental disabilities, it seemed to the Congress (and to others) that the Councils "service priority" funds should be targeted elsewhere. The 1984 "about face" on this issue arose in part out of the exasperation of many who found that the state rehabilitation agencies felt they had neither the authority nor the mandate to include (for example) individuals for whom a supported work program offered at least a hope worth trying. As a result, it seemed desirable to open up an alternative funding route, however small.

Since 1984, however, several things have happened that change this picture. First, the supported work projects have been replicated in a variety of settings in different parts of the country and hundreds of professionals have been attending conferences to learn how it is done. Second, Congress has modified the authority of the basic state grant program under RSA to make clear that such funds may be legitimately directed toward more severely disabled people for whom supported work is a goal. Third, the leadership of RSA in Washington has changed and it is clear that the messages going forth from RSA (which sends [sic] 20 times as much money just for employment as ADD can send [sic] for everything) intend that federal vocational rehabilitation funding be shared at the state level with the eligible developmental disabilities population. If Congress persists in mandating employment as a priority for the Councils, it will send a message that vocational rehabilitation agencies do not really need to take these changes seriously because developmental disabilities funding will continue to be available under the mandate of the federal Developmental Disabilities Act.

The Councils should continue to take a balanced view of all the components that contribute to productivity, independence and integration. These goals must be pursued everywhere, not just in the labor market, and each Council commingling began, yet they are responsible for producing data for us without which we would have been unable to answer many of your policy questions.

3. Policy Outcomes To Be Expected by Taking the CCDD Recommendations Regarding Special Projects

Due to my travel schedule, I have been unable to complete a response to this important questions. While I know the record must be closed today, I still wish to respond to you for your own and your staff's information. I apologize for this snafu.

4. Most Important CCDD Recommendations

Without question the most important CCDD recommendations are linked to resources. Dr. David Braddock's data clearly show the dramatic impact the funding events of the last six years have had on the DD programs. Their responsibilities have increased without a concomitant increase in funds. It is critical that the recommended authorization levels be adopted and that the authorizing committees advocate strongly for these levels in appropriations bills.

Increasing state flexibility with respect to priorities and clarifying the policy role of the DD Council are the most important recommendations pertaining to the Basic State Grant Program. The Protection and Advocacy recommendations regarding underserved groups and the related increase in funding are the most important Protection and Adocacy recommendations. The need to strengthen and expand the University Affiliated Program network and to ensure that every state has a UAP are the most important recommendations made regarding the UAP program. The revamping of the Special Projects authority to focus on national policy initiatives rather than local demonstration projects is CCDD's most important recommendation in this area.

5. Annual Report Requirements

In 1984, the DD program components, Councils, P&As and UAPS, were outspoken advocates to increase reporting requirements for themselves as well as for the Secretary of the Department of Health and Human Services. Since 1981 we have seen a dramatic reduction in the quantity and quality of data needed to monitor these programs. Because of OMB restrictions on data collection, reporting requirements need to be very specific in statute to enable an agency to query constituent agencies. The Report to Congress developed by the Secretary can only be as detailed and comprehensive as the data the agency receives from the program components. At this point the state data are more detailed than the FY 1985 report from the Secretary, but internal constraints preclude the administration's report from being as comprehensive as state reports would allow. Congress may wish to provide more specificity for the Secretary's Report on the programs.

The richness of information collected by Councils, P&As and UAPs (through their national associations) has been voluntary in nature and generally not supported by federal funds. Much of this data is appropriate to be collected and/or financially supported by the federal government and made available to Congress in the Secretary's report. The CCDD recommendations regarding data-collection under the Special Projects authority are intended to address

Congress in the Secretary's report. The CCDD recommendations regarding data-collection under the Special Projects authority are intended to address this concern.

6. Involvement of Minority Populations in Policy Development

Since this is not my area of expertise, I hesitate to offer specific suggestions. I do know that some years ago ADD gave several grants to develop awareness of and expertise in developmental disabilities to various grass-roots minority organizations. You may wish to see what recommendations were made in the final reports of those projects.

It is relevant to call attention to the fact that the disability rights movement crested a decade after the civil rights movement of the 1960s. Many of the concepts and strategies were consciously modeled after the principles and strategies expoused by the civil rights leaders, most of whom were members of minority groups. Thus there are policies affecting people with developmental disabilities being implemented today which owe very much to the models of thinking and acting that have been contributed to American culture by blacks and others.

People (other than elected officials) who make or effectively influence policy usually fall into one of three groups: 1) people who are placed in high-level, policy making positions in state or federal government and who work full-time at it; 2) people who work in university-based or free standing, non-profit or proprietary think tanks that are staffed by individuals with training or experience in policy analysis who are making a career of it; and 3) volunteers who are either board members of national, state, or local organiations or who serve on various ad hoc or permanent advisory bodies of which, of course, Developmental Disabilities Councils themselves are a good example. Another example of influencing policy at the local level can be found in the boards of Independent Living Centers, which were established under the Rehabilitation Act with the requirement that a majority of board members be themselves persons with disabilities.

The sophistication needed to function effectively as a policy maker in these settings is not conferred by a "parchment commission" signed by the CEO, or by affirmative action or even by the experience of disability itself. It takes time and the right experiences to become an "otherwise qualified" candidate for these activities. To the extent that people identified as black, hispanic, or Asian may have acquired the qualifications and are not otherwise preoccupied with pressing issues such as housing, poverty, teen age pregnancy, unemployment among youth or racial discrimination, they have usually found a welcome in work for people with disabilities. The national past president of one of the organizations in our coalition who is black told me that he had elected to work in the field of mental retardation because he saw in them a group that was even more "put down" than his own black colleagues. Finally, I would say that the best way to assure a meaningful participation by members of minority groups in policy making vis-a-vis developmental disabilities is to assure that members of such groups who are interested in becoming effective, whether as volunteers, as consumer advocates or as a career, should be assured of being able to acquire these competencies that are necesarry.

There are several avenues that can lead in this direction. First, there is access to internships, in government, on the Hill and in state and local counterparts, and in selected private organizations. The University Affiliated Facilities can fit into the picture as well. The task force that I chaired in 1983, which was asked to make recommendations to the ADD about the future of UAFs, addressed the need to develop centers of excellence in the analysis of policies affecting people with disabilities. We suggested that, in addition to the usual clinical specialities, some UAFs should establish concentrations in public administration and public policy. It was intended that they adapt the UAF model to provide interdisciplinary training to government agencies and research related to policy issues. Since then the Center for Community and Research Services at the University of Minnesota has achieved UAF status. It may also be noted that one of Dr. David Braddock's most esteemed colleagues at the University of Illinois' Institute for Study of Developmental Disabilities is of Asian descent.

7. The Older Americans Act

The CCDD Task Force on Developmental Disabilities worked closely with the CCDD Aging Task Force and I understand that a series of recommendations have been offered to the appropriate committees for amendments to the Older Americans Act which address the needs of people with developmental disabilities. The Co-chairs of that Task Force are Ruth Katz of the National Association of State Mental Retardation Program Directors and Curt Decker of the National Association of Protection and Advocacy Systems.

Sincerely yours,

Elizabeth M. Boggs, Ph.D.

Senator **Harkin**. Thank you very much, Dr. Boggs.

Dr. Healy, my first question is, are you in an ivory tower, after that?

Dr. **Healy**. I am sorry, Senator, I did not hear you.

Senator **Harkin**. Dr. Boggs has said one of the early criticisms of the university-affiliated programs is that they have lived in ivory towers, and I was just jesting about whether or not you felt you were in an ivory tower at the University of Iowa.

Tell me, in the State of Iowa, what is the current status of planning for implementation of P.L. 99-457, especially the new early intervention program? Has a lead agency been named?

Dr. **Healy**. The lead agency has not yet been named. The official response to the Department of Education is that we are awaiting the publication of regulations relating to 99-457, which has not yet occurred. It would be my personal interpretation that the Department of Education will in all likelihood be given that lead responsibility. We were one of the few States that initially started with birth-to-three services at the initiation of Public Law 94-142.

Senator **Harkin**. Do you have any idea how many people might be in this in Iowa?

Dr. **Healy**. The textbook approximation is that approximately 1 to 2 percent of every birth population, 1 to 2 percent of all newborns, would have significant disabilities that would qualify them for this type of service. That would be approximately 400 per year in the State of Iowa. At the present time, we are serving 900 children. The theoretical would be 1,200, but we are at the present time serving 900 children under three years of age or under 36 months of age.

Senator **Harkin**. In your opinion, do you think there are a sufficient number of related services personnel, occupational therapists, physical therapists, speech pathologists—all the other specialized people that will be needed to administer the multidisciplinary services that are called for?

Dr. **Healy**. I absolutely do not think a sufficient quantity of such persons are available, nor do our studies indicate that they will be available by 1991 when the full effect of this public law will have its effect. There is no question—and this feeling is also held by the Department of Education—that the numbers of physical therapists, occupational therapists and speech therapists are inadequate both quantitatively and qualitatively. Those that are available are not trained in the needs of the young child. Approximately 5 percent of the training effort devoted to all physical therapists in the United States are devoted to problems relating to children. And you can well imagine that even the infant receives less emphasis within that training.

Senator **Harkin**. So we are going to need some additional funds; is that what you are saying?

Dr. **Healy**. Absolutely, sir. There also is the opinion of the officials within the Department of Education in the State of Iowa that those funds that will become available for training under 99-457 will not be sufficient in any way to meet the training need. They will in all likelihood use those funds for in-service education of existing personnel and will not make any available for the pre-service training of those who wish to enter the professions in care service areas.

Senator HARKIN. Thank you very much, Dr. Healy.

Mrs. Hoyt, you testified that in 1985, New Jersey was the first and only State to adopt the complete Federal functional definition to be used in Federal law. Why haven't other States done it? Do you have any concept of why other States have not done this?

Mrs. HOYT. I think it has a lot to do with what Department within a State the law is administered out of. I think where the DD Council sits on the hierarchy within a State government and the people, where they come from, within their interest levels—I think it has a lot to do with that, at least, I know it does in our State of Massachusetts.

Senator HARKIN. Do you have any observations on that, Dr. Boggs?

Dr. BOGGS. Well, in fact, there are quite a number of States, and I believe Hawaii was actually considered to be the first, which moved substantively, even if not verbatim to extend services to persons whose developmental disabilities do not include mental retardation. In New Jersey, for example, we did see it desirable to make sure that when the new broader definition was put into effect, anybody who had previously been eligible as mentally retarded (or a similar person in future) would continue to be eligible even if he or she did not meet the criteria for the severity of disability that is associated with the DD definition.

I believe that the influence of "decimal dust" in this case has been extraordinary, because I think between 30 and 35 States have moved in some respect to change the agency that is the traditional MR agency in a direction toward being more accommodating. Certainly, that has happened in New York, for example.

The question of how this very small amount of money can be made to influence the larger activity and the additional State dollars and all that sort of thing—it is not an easy move to make. I think that this is where the policy analysis comes in. I think I said that originally, and I want to reemphasize it. You have to look at your own State government and decide where various responsibilities should be allocated. For example, Todd referred to the fact that he felt that the activity that he is involved in is an enhancement of independent living. The Congress in its wisdom has seen fit to assign the Federal dollars for "independent living" to the state vocational rehabilitation agency, and many people who are severely physically disabled, but not mentally retarded, look to that program and that agency more than to the MR agency for community support services.

So it has to be studied within the individual State in terms of what the people in the State want and what is workable or convenient in government, given how that particular government is structured.

Is that responsive to your question?

Senator HARKIN. I am just thinking about it. You are more or less advocating that you have a variety of different systems out there, that each State sort of do——

Dr. BOGGS. I am advocating States' rights, I suppose. It sounds funny coming from the position where I generally stand. But I am advocating that States are in fact different, and that their State structures are different, and that the State Councils are there to look at the generalities and the particularities and make them match.

Senator **Harkin**. It also depends on how those Councils are structured, does it not?

Dr. **Boggs**. Well, that is right, and the Council structure has been fairly well-established or set by the Congress. The rules for the composition of State Councils are sometimes hard to meet, but I understand why they are, and I think that nobody is asking for changes this time around, excepting I think that Assistant Secretary Elder's suggestion to modify the requirement for the parent of an institutionalized individual, I think that would probably make sense.

But basically, the requirements are there, and there is a requirement for the major State agencies to be there. And one of the most important things that the Councils do is deal with the interdepartmental problems.

I happen to have served this past year as vice-chair of a Governor's ad hoc task force on services to people with all types of disabilities, and the major problems we had were the problems where two or three departments have to come together and agree which part of the package they are going to undertake. We have—and this is something that Dr. Elder has actively promoted, to her credit—we have a real initiative now to deal with the transition from school to work by involving education, the DD agency, and the vocational rehabilitation agency (in three separate state departments) in a real collaboration. Those things have to be done; one of the important functions of a State DD Council is to bring those people together. There is a certain requisite membership of State agencies on the Council for that purpose.

Senator **Harkin**. Thank you.

Mrs. Hoyt, I want to come back to you on that question.

Mrs. **Hoyt**. I just think that what happens in a lot of States—and I can speak best, of course, to Massachusetts because that is where I live, and that is where I do my thing—basically, what has happened is that 20 years ago, one of the few agencies, parent groups, that was around advocating was that for persons with mental retardation, and thank God, because they gave parents like myself the courage to get involved as our children were born and go on.

I think what has happened over the years is that we have a lot of other disabling conditions that do not have the label of mental retardation attached to them, and the Councils must have equal representation of all of those different disabilities. And I think that is how we are going to get States to actually open up the doors, so that everybody has equal access. We are a changing group of people when we have many different disabling conditions now that need services that are very, very different than we had in the past for many, many reasons, and I am sure the Doctor could probably support that in a much more eloquent, intelligent way than I can as a mom.

Turrette Syndrome, for example. I am working now with a dad who has a son with Turrette Syndrome. His son cannot get access through the developmental disabilities group in our State, and this family system is ready to fall apart, and that is ridiculous. It does not make sense. The emotional things that are owning that family right now are much worse than the emotional things that are around some of the other families who have individuals with a cerebral palsy label and a mental retardation label.

So I think that again, when we are looking at futures and we are looking at changes, we have to pay attention to all of these things. And it is Federal law that mandates the States to do what they should do, and then it allows advocates like myself to take and use that. If it was not for the special education law in Massachusetts, 766, prior to 94-142, my son Rick would never have gone to public school. The law did not get Rick to go to school; the law gave me the tool to go to my State and to my school system and say my son will be here. And that is what I think we really are talking about.

Senator HARKIN. Thank you very much, Mrs. Hoyt.

Senator Stafford?

Senator STAFFORD. Mr. Chairman, I would like an opportunity to review the testimony today, and I do have some questions for each witness. But if it is agreeable to them, I would like to submit the questions in writing for them to answer at their earliest convenience.

Would that be agreeable?

Mrs. HOYT. That would be fine.

Senator STAFFORD. Thank you very much.

Senator HARKIN. I have some follow-up questions, too, that I want to ask. And I would just ask, if you could, since we are trying to move this fairly soon, if you could respond by April 23rd, if you could try to get them back.

Again, I want to thank you all for coming here today and testifying.

In closing, I just want to state for the record that the statement of Senator Hatch and the statement of Senator Weicker will both be included in the first part of the hearing today, without objection.

Also, we have the testimony of the American Psychological Association, and that will be included in the record; and an opening statement by Senator Paul Simon and Senator Cochran will be included.

Senator STAFFORD. Mr. Chairman, it is quite possible that Senator Weicker might have a question or two in writing as well, so if that right could be reserved to him.

Senator HARKIN. Certainly. That right will be preserved for everyone on the Subcommittee, and the record will remain open until that time until we get the written responses back.

[Additional material submitted for the record follows:]

American
Psychological
Association

Testimony for the Record
By
Orv C. Karan, Ph.D.
Waisman Center on Mental Retardation and Human Development
University of Wisconsin-Madison
on behalf of
The American Psychological Association
for the
United States Senate
Subcommittee on the Handicapped
Honorable Tom Harkin, Chairman

regarding the reauthorization of
The Developmental Disabilities Act

April 8, 1987

Submitted by
D'Amore and Doyle, Inc.

On behalf of over 87,000 psychologists throughout the country, The American Psychological Association appreciates the opportunity to share our views with the Subcommittee regarding the reauthorization of the Developmental Disabilities Act.

First, we would like to express our support for the legislation, particularly the interdisciplinary focus which brings together professionals, consumers and agency representatives who are working to improve the lives of our nation's developmentally disabled citizens. This Subcommittee has a strong track record of leadership and advocacy for developmentally disabled persons, and we are proud to support the work that the Subcommittee has done.

Our forefathers envisioned a country in which "all men are created equal," and, for many, America has become the "land of opportunity." Most children are encouraged to believe that with enough ambition and hard work they can become whatever they want to be; that is, unless they are developmentally disabled. For many of these youngsters, theirs is the land of limited opportunity.

Most adults who are developmentally disabled can be found in one of two distinct groups -- those who fit the limited community options which are available and those who do not. This latter group contains many who are needlessly confined to segregated settings or without any services at all.

It has only been in the last few years that this problem has even reached our national awareness. Partly because of our recent medical advances, which have resulted in saved lives and greater longevity for those who most certainly would have died less than a decade ago; partly because of our school systems, which provide public education to all youngsters, regardless of the extent of their handicapping conditions; and partly because of our technological breakthroughs which have contributed to overwhelming demonstrations of competence and have simultaneously raised our expectations about what people with developmental disabilities can accomplish, our society is capable of preparing a healthier, better educated, more competent population of developmentally disabled citizens. Yet many are entering an adult service system which is incapable of maintaining, let alone capitalizing on, this momentum.

If we have a technology that can contribute to an elderly population of developmentally disabled citizens who are fit, well, and involved, then why do we offer them instead precarious health, life in costly and complex facilities, and meaningless activity or unproductive roles in society? If we can prepare these youngsters for roles as contributing members of society, then why are more than 80% of them unemployed or underemployed within one year after completing their education? And, if we can now save the lives of catastrophically handicapped infants, then why do we, in turn, compromise the lives of their parents who often must shoulder the lifelong responsibility for their care alone?

A major part of the problem is that the adult service system in this country has been completely overwhelmed by the multiplicity of new and different demands that have been created by the breakthroughs and opportunities society has created in some of its other systems. The resulting costs to society in lost human potential and forced dependency are staggering.

The two most often identified major gaps in our adult services system are: (1) the lack of central coordination of service delivery, and (2) the lack of a single resource for long-term funding and employment-related services. These have been addressed in national studies without resolution.

THE VARYING NEEDS AND CHARACTERISTICS OF THE POPULATION

Congressional data indicate that approximately 8.8% of the population receive assistance for special education each year. Stimulated by PL 94-142, passed in 1975, we are now finding an unprecedented number of students with disabilities who are "graduating" from public school systems each year. It is estimated that 250,000 - 300,000 students graduate from special education programs annually of whom over 90,000 are developmentally disabled. These young adults, having been exposed to educational opportunities that were simply unavailable a decade ago, are a qualitatively different group of people than the generations which preceded them. Generally speaking, this new breed of young adults at all levels of handicap have more skills, more normal life experiences, and more potential than their earlier counterparts. Both they and their parents rightfully expect the same opportunities for further education and jobs that are available to their nonhandicapped peers.

As these recent graduates push the adult system from one end, residents of large public institutions, who are slowly being returned to the community, are pushing it from another end. It has been estimated that 6,000 individuals leave public-operated institutions each year to join those in community settings.

There are today approximately 110,000 mentally retarded and other developmentally disabled persons now living in public residential facilities. Although this represents only about 6% of the total number of such persons, they account for almost 41% of the total expenditure of Federal dollars spent on developmental disabilities in this country, or roughly $2.8 billion annually.

Many of these people grew up before the passage of PL 94-142 and therefore missed training opportunities which today are all but taken for granted. Theirs was the era of custodial care, and the primitive behaviors they acquired may have helped them cope with their impoverished institutional environments. Such behaviors are now inconsistent with successful integration within community settings. Service providers have really not had much experience serving these adults nor have they been well represented in the impressive community integration demonstrations to date.

Then there are those who have lived at home all their lives with their families. Most of these adults are middle aged or older, and because of the age, health, and/or death of their parents, are now just coming to the attention of the adult service system.

As advancements in medical technology and habilitative programming have dramatically impacted the life expectancy of these persons, a significant increase has emerged in the numbers of persons with developmental disabilities reaching old age. Yet, for many of them, in order to sustain their residence in the community, they must continue working when most of their nonhandicapped peers have long since retired.

RESPONDING TO THE CHALLENGES

As we attempt to respond to the community integration challenges ahead, we must be careful to avoid one of the major conceptual and procedural errors of the past, namely, that individuals with developmental disabilities be required to adapt to a limited range of community options. Under these circumstances, when a mismatch occurred, there was a tendency to blame the victim. Today we are just beginning to recognize that instead of simply attributing failure to the individual, components of the service system must be modified. It is becoming clearer that one's community placement success depends not on the degree of their handicap, but rather on what their community is willing and able to provide.

Many individuals, including professionals, parents, peers, paraprofessionals, even the person on the street, all play important direct or indirect roles in providing this support. Ways must be found to maximize the helpful participation of a wide variety of potential support people because a social life and interactions with others are important for individuals who are developmentally disabled.

Individuals with social ties have been found to show less vulnerability to stress and to be more socially adjusted. Social support appears to be a vital ingredient for positively contributing to one's mental and physical health.

The family is obviously an important part of this support network, and the role family members play is a critical factor in one's successful community integration. Through training and support, parents can become the "glue" that reduces the fragmentation so notorious in adult services and can ultimately contribute to the best community options for their family member.

Among those who fail to adjust to community environments there is a high prevalence of associated mental health difficulties. In fact, the prevalence of psychopathology among persons who are developmentally disabled is four to five times that of the normal population, and anywhere from 33% to 100% of those who fail in their community placements demonstrate obvious mental health difficulties. A recent national survey of community residential facilities for people who were developmentally disabled reported mental health difficulties to be the single most frequently identified condition among those residents with additional handicapping conditions.

Meeting the mental health needs of people who are developmentally disabled is a laudable "quality of life" goal, but, in fact, community service personnel in general currently neither have the skills or desire to effectively treat these mental health difficulties nor the service delivery systems to provide the type and continuity of resources required for effective treatment. Improving the adequacy and availability of such resources will depend on better training for both specialized and generic service providers.

The challenge of the future is to provide for a coordinated, collaborative service system that will enable the handicapped person to receive services in an expeditious and coordinated manner. The American Psychological Association would like to recommend the inclusion of the attached special projects in the reauthorization legislation so that some of the problems we have outlined can begin to be addressed.

Thank you for this opportunity to present our views.

Demonstration Projects for the Developmental Disabilities Act

The following is draft language to be inserted as Section 162(a)(1)(D) of the Developmental Disabilities Act:

(D) OF WHICH AT LEAST FOUR SHALL BE TO DEMONSTRATE THE EFFECTIVENESS OF A RANGE OF PSYCHOLOGICAL SERVICES FOR DEVELOPMENTALLY DISABLED PERSONS INCLUDING:

(1) ONE PROJECT PROVIDING PSYCHOLOGICAL SERVICES TO CHILDREN FROM BIRTH TO TWO YEARS OF AGE, INCLUSIVE, (AND THEIR FAMILIES) WHO HAVE OR ARE AT RISK FOR DEVELOPMENTAL DISABILITIES AS A MEANS TO ENHANCE THEIR PHYSICAL, SOCIAL, EMOTIONAL, AND/OR COGNITIVE DEVELOPMENT AND MINIMIZE THE DEGREE OF FUTURE IMPAIRMENT. THIS PROJECT IS TO BE COORDINATED WITH THE LEAD AGENCY IMPLEMENTING PART H OF PL 99-457;

(2) ONE PROJECT PROVIDING PSYCHOLOGICAL SERVICES FOR DEVELOPMENTALLY DISABLED INDIVIDUALS (AND THEIR FAMILIES) TO FACILITATE THEIR TRANSITION FROM INSTITUTIONAL SETTINGS TO INDEPENDENT LIVING ARRANGEMENTS IN THE COMMUNITY;

(3) ONE PROJECT PROVIDING PSYCHOLOGICAL SERVICES FOR DEVELOPMENTALLY DISABLED YOUNG ADULTS (AND THEIR FAMILIES) WHO ARE PREPARING TO LEAVE SPECIAL EDUCATION TO INCREASE THEIR POTENTIAL FOR COMMUNITY PARTICIPATION AND GAINFUL EMPLOYMENT;

(4) ONE PROJECT PROVIDING PSYCHOLOGICAL SERVICES TO AGED DEVELOPMENTALLY DISABLED INDIVIDUALS RESIDING WITH THEIR FAMILIES IN THE COMMUNITY TO MAINTAIN THEIR FUNCTIONAL LEVEL SO AS TO PREVENT THE NEED FOR PLACEMENT IN AN INSTITUTIONAL CARE SETTING.

FOR FY 1988, FY 1989 AND FY 1990, $1.5 MILLION IS AUTHORIZED PER PROJECT. ONLY DEPARTMENTS OR SCHOOLS OF PSYCHOLOGY THAT GRANT DOCTORAL DEGREES ARE ELIGIBLE FOR SUCH PROJECTS. PROJECTS ARE TO BE AWARDED FOR A THREE-YEAR PERIOD.

THE
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OF
ILLINOIS
AT
CHICAGO

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April 17, 1987

Mr. Bobby Silverstein, Staff Director
Senate Subcommittee on the Handicapped
United States Senate
Washington, DC 20510

Dear Bobby:

For the record, I wish to share some thoughts with you about the reauthorization of the DD Act.

UAFs

I am particularly concerned about the UAF section of the Act since Illinois does not now receive, nor has it ever received, funds under the UAF component of the Act. As far as I know Illinois and Texas are the only remaining large industrial states which do not participate in the UAF Program. I believe a total of 15 states do not now receive UAF grants from Washington.

As in many states, Illinois has serious state budget problems and the opportunity to compete for a federally-assisted UAF would be enthusiastically greeted here. In fact, in anticipation of such opening-up of competition I was recently appointed Acting Director of the University of Illinois at Chicago's UAF. Our current "UAF" consists of several state and university funded programs subsumed under the rubric of the Institute for the Study of Developmental Disabilities here at UIC. We also currently receive federal funds for several research and training projects, and we are a full-fledged member of the American Association of University-Affiliated Programs (AAUAP).

We lack, however, a UAF core grant to provide the fiscal and administrative "glue" necessary to bring additional coherence and commitment to our mission. We are also unable to compete for any special project funds for which only federally designated UAFs are eligible to compete.

My colleagues and I here at UIC remain unalterably opposed to the inclusion of any language in the DD Act reauthorization which would in any way impede or delay the holding of open competition for establishing new ADD-funded UAFs in those states which do not now participate in the Program.

It is my understanding that some persons have argued for a "trigger" in the Act in which a stipulated appropriations level would have to be reached before any expansion of the UAF network could take place. Having served on the ADD-convened review panel which has evaluated UAF applications for each of the past five years, I can assure you that the best UAF proposals are submitted under conditions of free and unfettered competition for grant awards.

I would therefore encourage the Subcommittee to consider statutory language permitting any state which does not have a UAF or a UAF satellite to submit a proposal at any time provided that that state's DD Council certifies or approves such an application. The application could be reviewed by an ADD panel during the traditional annual review of existing UAF/satellite proposals.

I also feel that the requirement for a two stage process (Feasibility Study and Full Proposal) is unnecessary and wasteful of federal and applicant resources. Anyone preparing a UAF grant proposal can simply be instructed to a) present feasibility data in the regular proposal, b) delineate the applicant's sponsoring UAF, and c) describe technical assistance which the applicant has sought and will continue to seek from an existing UAF(s). The proposal can then be evaluated on its merits and also be compared to other applicants under review. This would have the effect of stimulating existing UAFs to prepare better proposals because they would always be aware that the possibility exists for them to be "beaten-out" by a superior new applicant. An element of unfettered competition like that which occurs for R and T Centers would be healthy for the UAF network, in my opinion.

I realize that my suggestion will probably not be very well-received by many of my colleagues in the UAF network. But then, in formulating their position, the AAUAP probably didn't bother to consult individuals in those states which do not now receive ADD-UAF grants. In general, I also think that restricting any special project competition to the existing ADD-funded UAFs is a mistake. Any qualified organization inside or outside the network should be eligible to compete.

Special Projects

I also want to comment on the Special Projects section of the Act, Part E I believe. I am very pleased that advocates have chosen to recommend an earmarking of $1 million for national-level policy studies, including studies of the financing of services in the states. (I enclose a compilation of letters of support we received in connection with our National MR/DD Expenditure Data Base Project.) It disappoints me, however, that these funds have to be carved out of the already small sum of HDS discretionary grant funds ($2.4 million total in FY 1987). Couldn't the new $1 million Policy Study fund be created in addition to the existing Special Projects fund? I hate to see many potentially worthwhile projects across the country go unfunded because of the earmarking of special project funds.

I trust this information will be helpful to you in your deliberations, and look forward to continued collaboration.

Sincerely yours,

Dave

David Braddock, Ph.D., Associate Professor
of Community Health Sciences and Director

lc

cc: Senator Simon

DEVELOPMENTAL DISABILITIES PROGRAMS

Funding History

From: Federal Policy Toward Mental Retardation and Developmental Disabilities by David Braddock, Ph.D., Associate Professor of Community Health Sciences, School of Public Health and Institute for the Study of Developmental Disabilities, The University of Illinois at Chicago. 1987

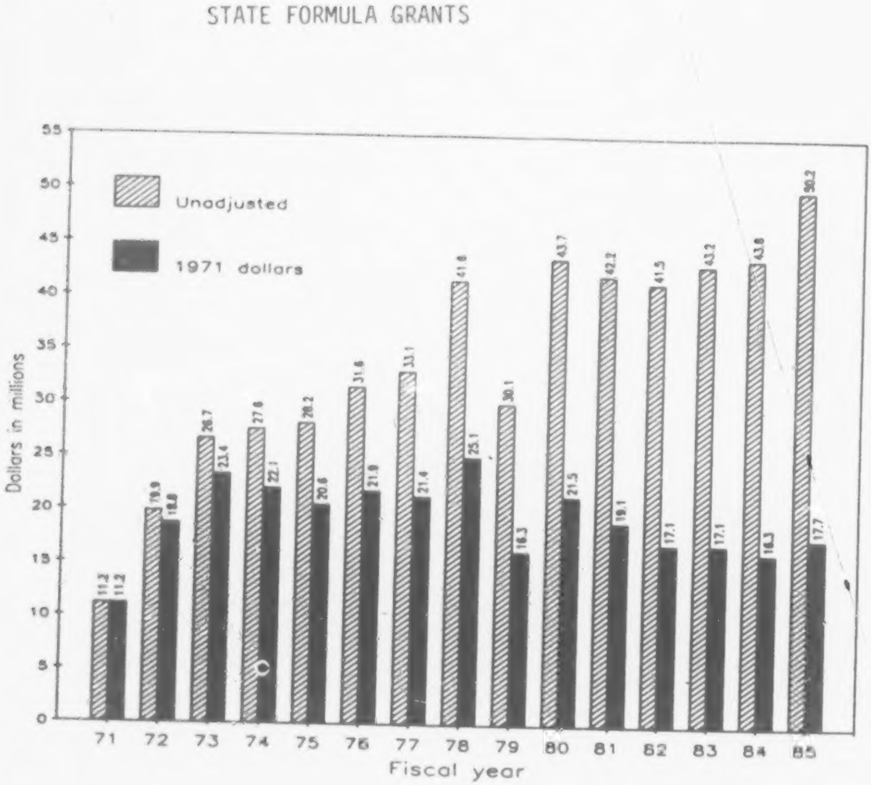

Figure 35. Federal Developmental Disabilities Act funding for State Formula Grants, excluding construction: FY 1971–85.

Expenditure Trends State Formula Grants were initially allocated under PL 91-517 in FY 1971, although FY 1972 was the first full year of funding. As illustrated in Figure 35, unadjusted budgetary increases were deployed for services from 1971 to 1977. A sizable increase was budgeted in FY 1978, followed immediately by a large reduction in FY 1979, beneath the FY 1977 level. A significant increase was again obligated in FY 1980, followed by essentially flat expenditure performance for FY 1981–84. In FY 1985, the program received a $50.25 million appropriation, a $6.5 million increase, nearly 15% above the FY 1984 level of $43.75 million.

Although the State Formula Grant Program has received a fairly large annual increase in appropriations five times since FY 1972, the program has been cut or essentially held at the previous year's funding level seven times. The inconsistent budgetary growth exhibited between FY 1973 and FY 1984 averaged only 6% per annum in unadjusted terms. In real economic terms, the picture is extremely bleak. The program's funding actually regressed 30% between FY 1973 and FY 1984. Expenditures in FY 1978, in fact, represented the high-water mark for the program on an adjusted basis; the FY 1978 figure was 47% higher than the sum budgeted for FY 1985.

PROTECTION AND ADVOCACY AGENCIES

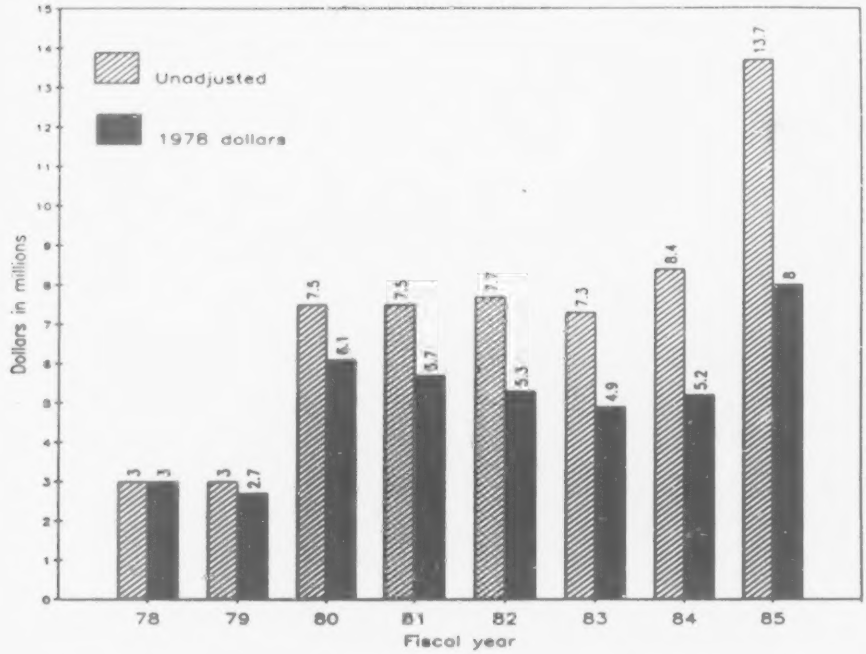

Figure 37. Federal Developmental Disabilities Act funding for Protection and Advocacy Grants: FY 1978–85.

The Protection and Advocacy program was authorized in the Comprehensive Rehabilitation and Developmental Disabilities Services Act Amendments of 1978. The program received an initial appropriation of $3 million in FY 1978. Funding was increased to $7.5 million in FY 1980 and $7.68 million in FY 1982. Expenditures fell slightly in FY 1983 to $7.32 million, but an increase to $8.4 million was budgeted in FY 1984. Appropriations for FY 1985 jumped to $13.7 million, an unadjusted increase of 63% over the FY 1984 level (see Figure 37).

UNIVERSITY AFFILIATED PROGRAMS

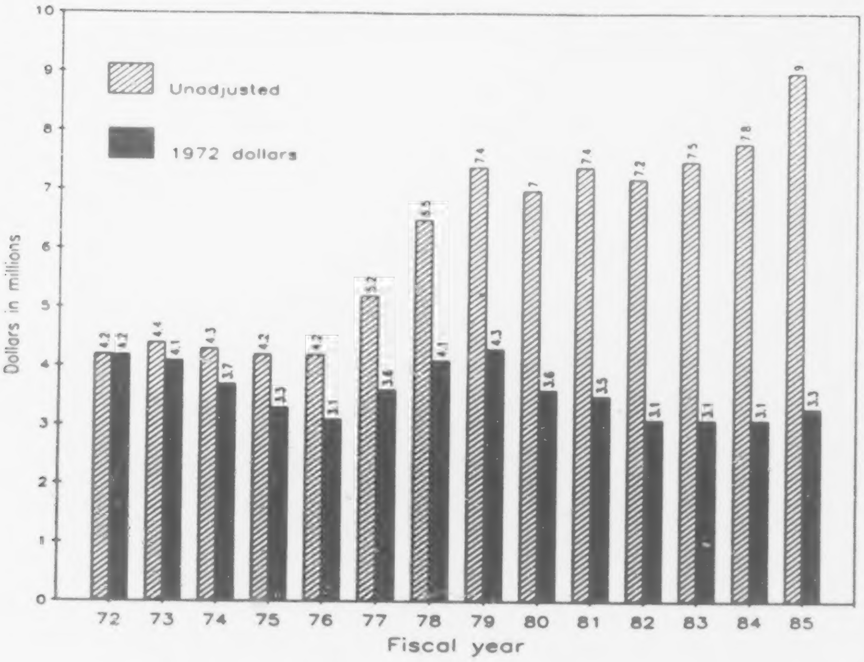

Figure 36. Federal Developmental Disabilities Act funding for UAFs: FY 1972–85.

Federal funding for the operation of UAFs was authorized with the passage of PL 91-517, the Developmental Disabilities Services and Facilities Construction Act. Funding of $4.25 million was initially deployed, and it remained at that level through FY 1976. Between FY 1977 and FY 1979, funding increased on an unadjusted basis by an average of $1.1 million per annum to $7.4 million. It remained at about that level for the next 5 consecutive years through FY 1984. The FY 1985 appropriation was increased to $9 million. In FY 1984, 43 UAFs and satellites were receiving assistance and several new satellite UAFs were scheduled to begin operation in FY 1985.

In real economic terms, UAF funding fell annually between FY 1972 and FY 1976, increased slightly during FY 1977–79, and diminished from FY 1980 to FY 1984. The FY 1985 appropriation is an adjusted increase of 6.5%. UAF funding trends in unadjusted and real economic terms are presented in Figure 36.

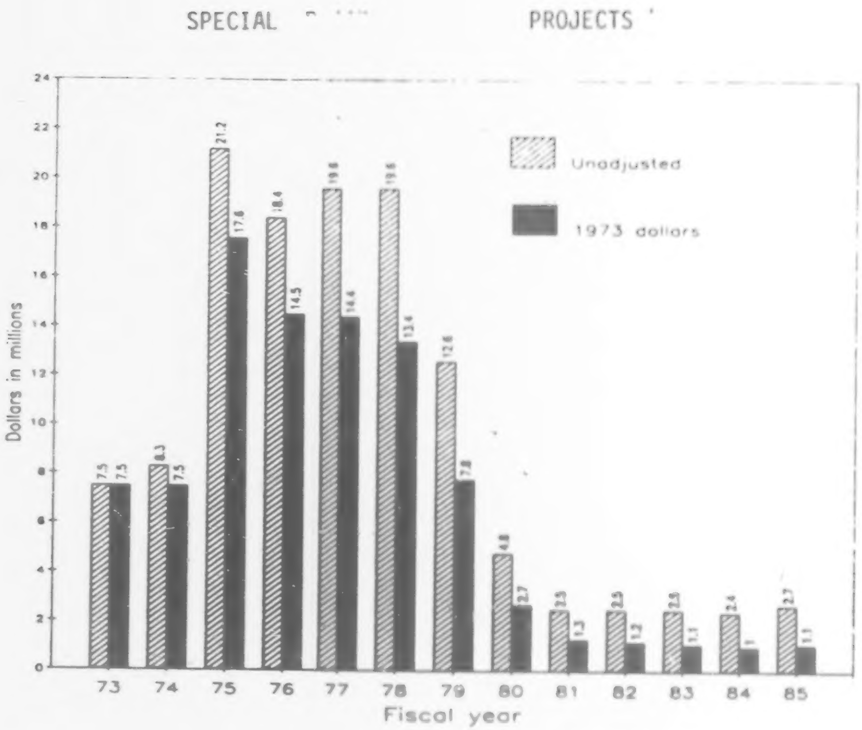

Figure 38. Federal Developmental Disabilities Act funding for Special Projects: FY 1973–85.

Funding for the Special Project authority has varied more widely on a year-to-year basis than any other DD Act–supported program. Initiated in FY 1973 at $7.49 million, funding for Special Projects almost tripled to $21.2 million in FY 1975. Funding ranged between $19.6 million and $12.6 million over the next 4 years, then plunged to $4.76 million in FY 1980, and $2.5 million in FY 1981. Spending was frozen at that level through FY 1984. A slight increase to $2.7 million was appropriated in FY 1985. In real economic terms, the budgeting of Special Project funds dropped every year between FY 1975 and FY 1984, as displayed in Figure 38. On an adjusted basis, the FY 1985 appropriation is an increase of 10% over the FY 1984 level.

FUNDING SUMMARY: DD PROGRAMS

Table 17. Developmental Disabilities Act funding summary, excluding construction: FY 1969–85 (dollars are in thousands)

FY	UAF Training Grants	State Formula Grants	Special Projects	Protection & Advocacy	Staffing Grants
1969					$8,358
1970					$10,990
1971		$11,215			$8,272
1972	$4,250	$19,919			$3,920
1973	$4,433	$26,674	$7,494		$3,384
1974	$4,335	$27,585	$8,275		
1975	$4,250	$28,176	$21,199		
1976	$4,250	$31,558	$18,432		
1977	$5,200	$33,058	$19,617		
1978	$6,500	$41,608	$19,567	$3,000	
1979	$7,420	$30,058	$12,568	$3,000	
1980	$7,000	$43,680	$4,756	$7,500	
1981	$7,400	$42,180	$2,500	$7,500	
1982	$7,200	$41,453	$2,500	$7,680	
1983	$7,500	$43,180	$2,500	$7,320	
1984	$7,800	$43,750	$2,447	$8,400	
1985	$9,000	$50,250	$2,700	$13,700	

Source: State Grant Program fiscal data for FY 1971–72 are from Braddock (1973, p. 103). All other data predating FY 1973 are from Braddock (1973, p. 137). DD state grants were used for construction projects in FY 1971–74. According to House appropriations hearings data, construction funding for these years was $1.796 million in FY 1972 (Office of Mental Retardation Coordination [ORMC], 1973, p. 65); $1.584 million in FY 1973 (OHI, 1975, p. 68). These funds are omitted from this table (see Chapter 7).

All fiscal data for FY 1973 and FY 1974 are from the FY 1975 House hearings (OHI, 1974). Data for FY 1976 are from the Office for Handicapped Individuals (OHI, 1977). Data for FY 1977 and FY 1978 are from FY 1979 House hearings (U.S. House of Representatives [House], 1978, p. 1139). Data for FY 1979–85 were obtained from the Budget Office of the Administration on Developmental Disabilities (Shirley Redmond, personal communication, December 12, 1984).

1986	$9,100	$51,250	$2,800	$13,900
1987	$9,180	$56,500	$2,500	$15,500

THE AMERICAN
OCCUPATIONAL
THERAPY
ASSOCIATION, INC.

STATEMENT OF

THE AMERICAN OCCUPATIONAL THERAPY ASSOCIATION

ON

REAUTHORIZATION OF THE

DEVELOPMENTAL DISABILITIES ASSISTANCE ACT AND

BILL OF RIGHTS

SUBMITTED TO

SUBCOMMITTEE ON THE HANDICAPPED
UNITED STATES SENATE

APRIL 20, 1987

OCCUPATIONAL THERAPY: A VITAL LINK TO PRODUCTIVE LIVING

1383 PICCARD DRIVE • P.O. BOX 1725 • ROCKVILLE, MARYLAND 20850-4375 • (301) 948-9626
Elnora M. Gilfoyle, OTR, FAOTA, *President* James J. Garibaldi, *Executive Director*

The American Occupational Therapy Association, Inc., (AOTA) is pleased to provide the Subcommittee on the Handicapped testimony concerning the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 98-527). Formed in 1917, the AOTA now represents over 44,000 occupational therapists and assistants, as well as students in training. Occupational therapy is a health profession which has a long history of providing services to individuals of all ages with developmental disabilities in schools, community programs and medical settings.

We enthusiastically support the current law and the four programs authorized by the Act: the Basic State Grant Program, the Protection and Advocacy Systems, the University Affiliated Programs and Grants of National Significance/Special Projects.

Specifically, we would like to provide supporting data for the following recommendation offered by the Consortium for Citizens with Developmental Disabilities regarding the University Affiliated Programs:

> The authorization of $1 million to provide support for five to seven pilot development and implementation training projects (each approximately $150,000 to $200,000) through 1990. The tasks of each pilot training project will be to plan, design and implement an interdisciplinary training program to help prepare allied health professionals needed to provide early intervention services.

Qualified caregivers in early intervention, across many different disciplines, are critically needed. The Education of the Handicapped Act Amendments of 1986 identifies the family as the focus for early intervention and requires an interagency system of education, health, social and developmental services to provide care for infants and toddlers with developmental delay. Currently, services for infants throughout the country are found in hospitals, public and private schools, private non profit community agencies, child care settings, and in parent-sponsored organizations. These programs are staffed by a variety of professionals including occupational and physical therapists, teachers, psychologists, doctors, social workers, communication specialists, nurses, and other allied health professionals.

Need for Specialized Training in Early Intervention for all Professionals

All professionals working with very young children must possess knowledge of both typical and atypical infant growth and development (Allen, Holm and Schiefelbusch, 1978). In addition, early childhood service providers must be able to work and communicate with parents and members of other professional disciplines (Anderson and Hinojosa, 1984; Bristol and Gallagher, 1982; Bromwich, 1981).

In April of 1984 the National Council for Exceptional Children convened a panel to address the unique personnel preparation issues associated with the birth-to-three population. In a follow-up meeting held at George Washington University in Washington, D.C. in September, 1984, four basic assumptions were discussed:

- Individuals who work with at-risk and handicapped infants and their families require information and skills different from personnel working with the 3-5 age group, thus, training programs should reflect these differences.
- The focus of intervention for the birth-to-three population should include the primary caregiver(s) and family members, thus, training programs should reflect this emphasis.
- Intervention with infants and their families requires maturity and judgment, thus, training programs should offer substantial opportunity for gaining practical experience.
- Intervention with infants and their families often requires coordination of many disciplines and agencies, thus, training programs should reflect this need (Bricker, 1984).

The AAUAP is uniquely qualified to address these interdisciplinary training needs since that is the essence of their mission.

Need for Specialized Training for Occupational Therapists

Experts in pediatric occupational therapy have recognized the same needs as described above. The Maternal and Child Health Training Program of the United States Department of Health and Human Services awarded funds to Boston University to convene a symposium of thirty-three experts in pediatric occupational therapy in June, 1986. A presymposium survey was sent to 121 state representatives of the AOTA and occupational therapy curriculum directors. They identified six major issues in pediatric occupational therapy practice needing immediate attention: professional preparation, clinical practice, collaborative relationships with other professionals, efficacy of treatment, public relations and reimbursement.

The issues of professional preparation and education drew the most comments regarding the need for change. Sixty-nine percent of the respondents felt that additional topics needed to be covered in professional preparations such as family dynamics, working with parents who have a child with special needs, collaborative and consultation skills, and supervised pediatric experience (Boston University, 1986).

Degree programs in occupational therapy furnish entry-level knowledge of human development and behavior throughout the life cycle, including sensorimotor, cognitive, and psychosocial components. There currently are 64 undergraduate programs nationwide that offer professional training in occupational therapy either at the master or baccalaureate level. Nine graduate programs offer a specialty in some area of pediatrics. Most programs include pediatric training in their human development and behavior courses. However, these courses typically do not focus on the specialized skills needed by occupational therapists to work with families or infants. As knowledge of early growth and development and family-infant programming has exploded in the last ten years, the ability of entry-level occupational therapy education programs to incorporate this information varies across the country.

A 1982 survey of 150 pediatric occupational and physical therapists in Nebraska and Iowa revealed that only 29 percent of therapists had been taught to work with families/parents (Gabriel, 1982). The most frequent source of post-graduation training was reading (70 percent), attending a workshop (69 percent), and interaction with colleagues (65 percent). Clearly, therapists are seeking specialized training in this area as indicated by 87 percent of respondents who wanted to learn more about parent training. Ninety-five percent of the respondents indicated that training therapists to work with parents would make pediatric therapy more effective.

The need for additional training is reinforced by a recent survey of thirty-four pediatric occupational therapists working in Massachusetts in early intervention programs (Boston University, 1985). One-third of the respondents reported they needed additional training in early development, specific therapeutic techniques, and family dynamics. The educational format preferred by almost half of all respondents was workshop training.

Need for Increasing Occupational Therapy Manpower in Early Intervention

The shortage of occupational therapists to provide services for families and their infants and children with disabilities is critical. For example, directors of the state plan grants available through PL 98-199 were surveyed regarding their manpower needs specific to early intervention programs. A shortage of therapists (occupational, physical and speech therapists) available to work with children ages zero through three years was reported by 96 percent of the 50 states surveyed. Moreover, 82 percent of the states expected these shortages in the birth-through-three-year programs to continue (Harbin and Meisel, 1986).

Of the 44,000 members of the AOTA, approximately 33 percent of all occupational therapists and 20 percent of occupational therapy assistants identify their primary caseloads as pediatric- i.e., birth through eighteen years (AOTA, 1986). Another 20 percent of therapists and assistants have mixed-age caseloads of adults, adolescents and children. In all, there are approximately 20,000 occupational therapy personnel treating children nationwide. Only 7 percent of pediatric occupational therapists identify their primary services as directed to children one through four years of age and less than 2 percent of occupational therapists work primarily with children during the first year of life.

That occupational therapy practitioners are interested and experienced in working with children is undisputed. In fact, the percentage of therapists specializing in pediatric practice has increased from approximately 25 percent in 1973 to 33 percent in 1986 (AOTA, 1986). However, it is clear that the majority of pediatric therapists are treating children ages five through 18 years.

Conclusion

We appreciate the opportunity to comment on the reauthorization of PL 98-527, the Developmental/Disabilities Assistance and Bill of Rights Act. Specialized training for occupational therapists in early intervention is needed in order to fill a critical manpower shortage of qualified therapists working in this field. The AOTA supports the Consortium for Citizens with Developmental Disabilities recommendation to provide the University Affiliated Programs with $1 million in training funds to prepare allied health professionals to work in early intervention programs. We believe this will help prepare qualified professionals to develop the individualized intervention services mandated by the new early intervention program in the Education of the Handicapped Act Amendments of 1986.

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Washington, D.C. 20591

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202-267-3232 TDD

An Independent
Federal Agency

April 24, 1987

Senator Tom Harkin, Chairman
Subcommittee on the Handicapped
Room 113
Hart Senate Office Building
Washington, DC 20510

Dear Senator Harkin:

On behalf of the National Council on the Handicapped, I am pleased to submit the enclosed report regarding the reauthorization of the Developmental Disabilities Act. This legislation serves one of the most vulnerable segments of the disability community who are too often denied the most basic rights because they are perceived as being "too severely" disabled to benefit from education and training. Through the reauthorization of the Developmental Disabilities Act, as well as the implementation of other laws within the Subcommittee's jurisdiction, it is our hope that all persons with disabilities will be able to live and work independently in their communities.

We hope that this report is helpful. Please let us know if we can be of further assistance.

Sincerely,

Sandra S. Parrino

Sandra S. Parrino
Chairperson

Enclosure

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**An Independent
Federal Agency**

NATIONAL COUNCIL ON THE HANDICAPPED

REPORT ON THE REAUTHORIZATION

DEVELOPMENTAL DISABILITIES ACT

April 24, 1987

The Developmental Disabilities Act which is being reauthorized this year serves one of the most vulnerable segments of the disability community. These persons are often relegated to live in institutions apart from their family or friends. They are often denied the most basic rights because they are perceived as being "too severely" disabled to benefit from education and training. The National Council on the Handicapped, an independent Federal agency, is charged with making broad-based policy recommendations regarding the rights and needs of persons with disabilities. The Council submits the following recommendations, which reflect consultation with many experienced and knowledgeable advocates for persons with developmental disabilities.

Developmental Disabilities State Councils (DD Councils) and State Plans

The Developmental Disabilities State Planning Council and the State Plan represent the core of the developmental disabilities program. Many Developmental Disabilities Councils have become potent catalysts for change at the state and local levels. Through their efforts additional state and local monies have been accessed. Likewise, the DD state planning process has evolved over the years as a vital tool for assuring that the needs of individuals with developmental disabilities are adequately met. With this in mind, the Council offers the following recommendations.

Many agencies representing children and adults with developmental disabilities have recommended that the State optional priority area should be fully reinstated and its selection should be at the discretion of the states. Further, it should not be conditional upon a demonstration that the federal priority areas are no longer needed, but upon a demonstration of the need for such state priority activities to the development of a comprehensive array of services. The Council believes that Federal programs must maintain a certain degree of flexibility in order to meet the unique needs of state and local communities. It is our understanding that while the existing priority areas of alternative community living arrangements, case management, child development services and employment-related activities are comprehensive, there are many activities which simply do not fit into these four priority areas. Thus, by allowing each state to choose an optional priority area, the Subcommittee will assure that critical issues are addressed while at the same time allowing each state to foster creative programming for the benefit of their citizens with developmental disabilities.

The Council is also concerned with the prevention of both primary and secondary disabilities. In our report, Toward Independence, we clearly delineated the steps which we feel are necessary in order to take a comprehensive approach to the prevention of disabilities. However, it is our understanding that several DD Councils are already engaging in a number of activities which are designed to prevent developmental disabilities from occurring. We therefore recommend that prevention be added as another priority in which a state may engage. There are two critical reasons for this recommendation: First many developmental disabilities can be prevented or significantly ameliorated through public education and awareness.

Second, many adults with developmental disabilities are experiencing an increase in secondary disabilities. For example, it is becoming apparent that persons with cerebral palsy often experience premature arthritis and other muscular-skeletal problems. Thus we recommend that prevention be added as one of the state priority areas.

The composition of the State DD Council has been largely effective in the past. Clearly it is extremely important that consumers, parents and/or guardians, service providers and appropriate state agencies representatives come together to discuss the problems faced by persons who are developmentally disabled. It has come to our attention that parents or guardians of persons with developmental disabilities may not be adequately represented on State DD Councils. The current legislation stipulates that the parent or guardian of an institutionalized person with a developmental disability should be a member of the State DD Council. However, within the developmental disability community, there is a strong thrust towards deinstitutionalization and the development of comprehensive community based services. With this being the case, some states are having difficulty finding parents or guardians to serve on the State DD Councils. We strongly support this trend toward the provision of community based services, not only for persons with developmental disabilities, but for all persons with disabilities. In addition, it is important to recognize that parents and/or guardians of persons who have recently been deinstitutionalized often face difficult problems, many of which may require changes in state and/or local policy. We therefore strongly recommend that the parent or guardian of a person who has recently been deinstitutionalized be represented on the State DD Council.

Reflecting the trend in our population as a whole, many persons with developmental disabilities are becoming elderly. As these individuals become older, it is likely that they will have unique service needs which must be met. In order to address this concern, the plan which is required by the Older Americans Act should be added to the list of other state plans for federally assisted programs to be described in the DD State Plan. This will assure that long-range systematic planning occurs for persons with developmental disabilities. As increasing numbers of developmentally disabled persons become older there will be adequate services to meet their needs.

Protection and Advocacy Systems (P&A's)

Over the years state wide Protection and Advocacy Systems have been a vital component of the Developmental Disabilities program. Because many persons with developmental disabilities are at risk of becoming institutionalized, many state P&As have been extensively involved in securing adequate community-based services for these individuals. Moreover, P&As have also assisted parents of children with developmental disabilities in their efforts to secure the necessary special education and related services in the least restrictive environment which will enable these children to actively participate in society. With these thoughts in mind we offer the following recommendations.

Public Law 94-142 the "Education for All Handicapped Children Act" was signed into law over a decade ago to assure the delivery of appropriate educational and related services to children with disabilities.

Prior to its enactment many of these children, especially those with developmental disabilities, either received an education which did not meet their needs or received no education at all. While much progress has been made in the field of special education in recent years, the Council remains concerned that the goals of the law have not yet been realized. The law mandates that all children with disabilities receive a free and appropriate public education in the least restrictive environment. Yet recent research done by the Council suggests that many children with disabilities, especially those children with severe disabilities, are being educated in segregated environments entirely apart from their non-disabled peers. The Office of Special Education has initiated a comprehensive monitoring system designed to reflect the strengths and weaknesses of states in implementing the mandate of Public Law 94-142. While this is a laudable first step, the Council believes that state and local education agencies must work together with parents and advocates to assure that the spirit and intend of the law are implemented. We suggest that State P&As be provided with reports from the Department of Education and state monitoring reports of local education agency activities. Such open sharing and communication of compliance information can only strengthen the implementation of Public Law 94-142.

While it is true that persons with developmental disabilities who are members of racial and ethnic minorities suffer the same indignities as other persons with developmental disabilities, there are special and unique problems that these individuals face because of the lack of awareness of their cultural differences. In addition, prejudice and racial discrimination continue to exclude a great number of nonwhite persons from full participation in all aspects of society. The Council has heard extensively from disabled persons who are members of racial and ethnic minorities concerning the dual discrimination which they often experience. The Department of Health and Human Services has provided funds in the past for P&As to develop outreach programs for minority persons with developmental disabilities. It is our understanding that these outreach programs were extremely successful and lead to improved services for a number of minority persons. The Council recommends that a specific mandate to meet the needs of underserved minority persons with developmental disabilities be added to the Act. Such a mandate will assure that these individuals gain access to services which will enable them to live and work in their communities.

The Council is also concerned that P&As must be encouraged to excel in their outreach efforts so that persons with developmental disabilities and their families are made aware of the expertise and services available. It is our understanding that current outreach efforts take place on a state by state basis. These outreach efforts include newsletters, public service announcements and parent training conferences. While these efforts are laudable, we recommend that greater emphasis must be placed on public information efforts so that all persons with developmental disabilities are aware of the services provided in their respective states.

University Affiliated Programs (UAP's)

University Affiliated Programs provide training to a wide variety of professionals and paraprofessionals who work with developmentally disabled individuals. Further, these programs (and their satellites) provide a number of direct services to both children and adults with developmental disabilities. The Council feels that these programs provide very valuable services. We suggest that this segment of the legislation be amended to authorize two new training programs to be conducted by UAP's.

During the last weeks of the 99th Congress, Public Law 99-457, the "Education of the Handicapped Amendments of 1986" was passed and signed into law. This landmark legislation for the first time, mandates that disabled infants and toddlers be serve at birth.

Further the new law significantly expands the existing preschool incentive grant programs and thus expand services to disabled youngsters who are three to five years of age. The Council is delighted with this new legislation and we note with pride that the expansion of the mandate of Public Law 94-142 to serve disabled children at birth was a major recommendation contained in our report, Toward Independence. Many experts have suggested that the mandate of Public Law 99-457 will increase the already growing demand for trained allied health professionals to work with youngsters with developmental disabilities. The Council recommends that small pilot projects be initiated which will plan, design and implement interdisciplinary training programs to help prepare allied health professional (and paraprofessionals) to work with young children with disabilities. These small pilot projects must not be conducted in a vacuum but should have significant input from parents of children with disabilities. While we respect the important role these professionals play in improving the lives of these youngsters, nothing can supplement the insights gained by parents who have raised these children.

The Council firmly believes that more persons with developmental disabilities must be enabled to live and work in their own communities. Integration into the community requires that a variety of services be provided at the local level which may not be currently available. These services may range from the provision of personal care assistance for two or three hours a day to extensive habilitation and training programs. The Council has held forums throughout the country, an overwhelming number of disabled persons we have talked to, want desperately to live on their own. But in order to gain this independence these individuals are painfully aware that a community-based service system must be designed to meet their needs. We recommend that the Developmental Disabilities Act be amended to authorize demonstration training programs for professionals and paraprofessionals to provide direct services to developmentally disabled persons in the community. In the early intervention training mentioned above, we stressed that parents of disabled children must have input into this process in order for it to be successful. Likewise, disabled adults must have direct input into these training programs in order for professionals and paraprofessionals to truly understand their needs. We believe that Centers for Independent Living (authorized by the Rehabilitation Act of 1973 as amended) could be excellent resources for

UAP's undertaking such training programs. While we recognize that these training programs should be geared to meet the needs of developmentally disabled persons who are being deinstitutionalized, we feel that disabled persons who are already living in the community can provide invaluable insights.

Definitional Issues

In recent years there has been increasing emphasis placed on the employment of persons with disabilities. The Council is committed to increasing employment opportunities for persons with disabilities, and we have made several policy recommendations in this area. During the recent reauthorization of the Rehabilitation Act, we recommended that greater emphasis be placed on providing technology in the workplace.

We recommend that the Developmental Disabilities Act be amended to include the term "applied technology" and should pertain not only to that technology which relates directly to the workplace but also to education, transportation, independent living and other community living arrangements. We believe that technology holds the key to greater independence and productivity for disabled persons, especially those who are developmentally disabled.

Finally, we suggest that the term "case management" be more broadly defined to encompass advocacy and community integration activities. Expanding the definition of case management to include these services will help ensure that more persons with developmental disabilities receive appropriate community based services.

NCPERH

National Consortium on Physical Education and Recreation for the Handicapped

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Reauthorization of the Developmental Disabilities Act

Subcommittee on the Handicapped

Committee on Labor and Human Resources

United States Senate

Washington, DC

Prepared Statement

of the

National Consortium on Physical Education and Recreation for the Handicapped

Dr. Michael W. Churton
Chair: Legislation Committee

Appalachian State University

Boone, North Carolina
March 31, 1987

Preface

The National Consortium on Physical Education and Recreation for the Handicapped is an organization which promotes, stimulates, encourages, and conducts professional personnel preparation and research in physical education and recreation for the handicpped. The NCPERH provides for public information and education, promotes the development of programs and services, and disseminates professional and technical information to its membership.

The NCPERH succeeded the National Ad Hoc Committee on Physical Education and Recreation for Handicapped Children and Youth, formed in 1973; serving as a means of assuring the continuation of the pursuit of the aims, activities and services of the committee on behalf of the physical educzation and recreational needs of the handicapped.

The NCPERH consists of practitioners, professionals, and parents who represent numerous institutions of higher education, public and private schools, hospitals and insitutions, and families . The NCPERH is the only organization in the country that interfaces the areas of physical education and recreation for the handicapped as specified in its charter and by-laws.

NATIONAL CONSORTIUM ON PHYSICAL EDUCATION AND RECREATION FOR THE HANDICAPPED

PART I

PURPOSE: To demonstrate that physical education and recreation are intregal parts of the developmentally disabled ability to achieve their maximum potential through increased independence, productivity, and intergration in the community.

Overview

Physical Education for the handicapped is a comprehensive service delivery system designed to improve the psychomotor functioning and independence of the developmentally disabled. Services include psychomotor assessment, individualized physical education and recreation programming , community integration and programmatic evaluation. The goal of physical education for the developmentally disabled is to the prepare ,and support and individual's potential and capabilities in becoming an active and productive member of his or her community to whatever degree possible. The delivery of physical education services enables the developmentally disabled to develop those psychomotor competencies needed for successful work performance, health and well-being, leisure and sport participation and for socialization experiences among handicapped and non-handicapped peers (Auxter & Pyfer, 1985 and Churton, 1985).

The National Consortium on Physical Education and Recreation for the Handicapped (Bundschuh, 1984) indicated that the role of the physical education for the disabled service provider may include:

...Direct Service Delivery Specialist: The individual teaches developmentally disabled in the regular physical education self-contained, resource, or remedial classrooms in order to prepare the individual for successful transition from school to community and work.

... Teacher-consultant: The individual serves as a resource person to community personnel including work related staff, agency personel, teachers, and parents.

Physical education for the developmentally disabled provides designated curriculum area within the array of services delimited under the generic area of special education. However, physical education is the only curriculum area specifically cited within the EHA definition of special education (EHA-Part A, Sec. 602). As an intregal part of special education, physical education services are provided to the developmentally disabled from the preschool level through adulthood and includes services for the severely and profoundly handicapped at school and in community programs.

Emphasis at the preschool level is concerned with the development of appropriate play , socialization and motor skills, behaviors. Basic motor skills are required for children to enjoy the benefits of play. Should children experience difficulty in basic motor skills, intervention by a physical educator may be required. Certainly , the motor foundation established during preschool enables the handicapped child to participate in normalized activities with their non-handicapped peers (Bowers, 1983).

The elementary school level focuses upon the further development of basic motor skills, physical fitness, perceptual-motor abilities, fundamental patterns, and individual and group activities. Development occurs through individualized educational programming using a variety of instructional and behavioral technological methods. This permits the developmentally disabled the opportunity to participate in social and leisure activities within the community in an intergrated setting.

The intermediate age period will include an emphasis on physical fitness and socialization through the participation in team games, sports, and activities. The disabled child should be given the opportunity to develop not only those psychomotor skills required for sport and game interaction with peers, but also those psychomotor skills needed for maintaining a healthful lifestyle and for obtaining employment in the community.

The emphasis in high school and the post-school period is on those lifetime activities which will enable the individual to enjoy recreational and leisure time pursuits. In addition, the maintaining of adequate physical fitness and health together with the development of psychomotor skills needed for successful employment are stressed.

The Need for Physical Education

The importance of physical education as a required service for the developmentally disabled is due to the cause-effect relationship that exists between the disabled child and his or her success during the school-aged, transitional, or adult period of his/her life . The contributions that are made by the delivery of physical education services improves not only the psychomotor functioning of the child during and/or after school activities, but it also prepares the developmentally disabled for the psychomotor demands of healthful and qualitative lifestyles, interpersonal relationships, and for successful work performances. (Auxter & Pyfer, 1985).

The Developmentally disabled as with non-handicapped children are in need of a quality physical education program in order to fully participate in cultural and traditional activities of early childhood (play), school years (games and competitive sports), and adulthood (leisure activities). A quality physical education program prepares handicapped children to develop their psychomotor needs which will allow them to choose or to be encouraged to choose activities and social situations with their handicapped and non-handicapped peers.

The curriculum for the developmentally disabled lies in the developmental principles supported by Bowers (1983), DePauw & Seaman, (1984), and Auxter & Pyfer, (1985). Harrow (1969) in her taxonomy of the psychomotor domain indicated six levels of development including reflexive, fundamental movements, physical abilities, perceptual abilities, skilled movements, and non-discursive communication. Success in the psychomotor domain allows handicapped children the societal, health, work, and physical skills that enables the disabled to become productive and useful members of society.

School-age Period

School age psychomotor needs of the developmentally disabled include those skills necessary to participate in play and other activities including games, sports, and leisure programs. Traditionally, this has been the role and purpose of a quality physical education program for public and private schools.

Evidence is presented which demonstrates that a quality physical education program can improve those psychomotor skills necessary for The developmentally disabled to participate in the psychomotor, social, and play aspects of the school-age period . The physical education program can make a significant contribution during the school-aged period by:

1. Developing prerequisite motor skills necessary for participation in self-fulfilling childhood games and social activities.
2. Developing physical fitness for the maintenance of health.
3. Developing ambulatory skills to master mobility in domestic and community environments.
4. Developing recreational skills for independent functioning in the community.
5. Developing physical and motor prerequisites for vocational skills required for independent living.
6. Developing physical and motor prerequisites for self-help skills required for independent living (Auxter & Pyfer,1985 and Fait & Dunn, 1984).

Research in the area of physical fitness for the mentally retarded and other handicapping conditions have supported the fact that physical fitness can be improved in the developmentally disabled. By developing physical fitness, the developmentally disabled individual has the physical vitality and endurance to learn more complex motor skills, participate in fitness oriented activities with non-disabled peers, and receive the health and well-being benefits of aerobic and cardio-respiratory development.

In addition, it has been demonstrated that adequate levels of physical fitness enables the disabled and nondisabled individual to enjoy more success on the work force by experiencing less off-job time due to illness and health related factors. Further, with adequate levels of fitness, clients will have more flexibility in the learning and selection of job skills required for employment. (Corder, 1966 &1969; Oliver, 1958; Solomon and Prangle 1970; Rarick, Dobbins, and Broadhead 1976; Courtney 1972; Greenfell, 1965; Cavanaugh 1968; Nunley, 1965; Britt, 1968; Goodwin, 1970; Funk, 1971, Wepman, 1982; American College of Sports Medicine, 1975; Rarick, 1980; Cooper, 1970; Miller & Allen, 1982).

Sport Competition

The developmentally disabled who wish to participate in competitive sport activities have many opportunities in which to compete. The Amateur Sport Act of 1978 (PL 95-606) established a Committee on Sports for the Disabled within the U.S. Olympic Committee. Organizations who have membership in this Committee include The United States Amputee Athletic Association, United States Association for Blind Athletes, National Association of Sports for Cerebral Palsy, National Wheelchair Athletic Association, American Athletic Association for the Deaf, the National Handicapped Sports and Recreation Association, and Special Olympics, Inc.

Quality physical education programs can help the disabled students who choose to compete in these competitions to become better trained and conditioned and to receive the full benefits of sports competition (Winnick, 1984 and Miles, 1985).

Motor Development

The role and purpose of a quality physical education program is to maximize the motor performance of the developmentally disabled on the many specific skills within the physical education curriculum. The adapted physical education teacher must determine through specific assessments and appropriate intervention strategies to ensure that learning occurs. Through a quality physical education program, motor performance can be improved and activity levels raised so as to permit the disabled child the opportunity to learn more complex motor tasks and to enjoy participation in activities with their nondisabled peers. Irregardless of handicapping condition, motor learning and performance can be facilitated through a well developed and qualitatively presented physical education program (Auxter & Pyfer, 1985; Iyriboz, 1984; McCubbin & Shasby, 1985; Porretta, 1985; Lavay, 1984).

"Least Restrictive Environment"

The practice of mainstreaming of the disbaleГ- students is the least restrictive educational placement of that child in an environment that best fits his/her educational needs. Physical education has been effected by "mainstreaming" as has the generic areas of special education. Research suggests that for those disabled children who have the psychomotor abilities to participate in the regular physical education program , then it would be in the child's least educationally restrictive interests to be placed in this program. However, when children are placed in the regular physical education solely for an affective/social basis, the disabled child tends to suffer in his motor performance. The advantage of teaching disabled students in the regular physical education setting is for disabled children to learn culturally relevant social skills, psychomotor skills, and interpersonal skills which can be generalized to meet transitional, employment, and leisure demands. A quality physical education program can facilitate the development of those skills which will allow the disabled child to not only improve motor functioning in the regular physical education program, but also improve affective skills as well (Dunn & Craft,1985; Sherrill, 1985; Karper & Martinek, 1985; Auxter & Pyfer, 1985).

Health and Wellbeing

Increased concern over the incidence of heart disease, obesity, and high blood pressure has generated considerable interest in cardiorespiratory or aerobic physical fitness. The importance of physical fitness to health is producing growing support for physical fitness as a major objective of physical education programs for the disabled . Recognition has grown in recent years of the importance in the health benefits of enhanced physical fitness to the typically less active disabled population. Due to a combination of factors including physical inability, overprotection, self-consciousness, attitudinal, and inaccessibility of facilities and programs, developmentally disabled individuals usually engaged in less daily physical exercise than do their non-disabled peers. This reduced level of daily exercise negatively effects the functional capacity of their neuromuscular and cardiorespiratory systems producing a general overall decreased level of physical fitness. The rehabilative value of exercise has been universally accepted as an adjunct in the return of injured persons to normal functioning as well as in retarding the progress of some diseases (Cooper, 1970; Corbin, 1980; Getchell, 1983; Haskell, 1980; Hutman, 1979;)

Chronically ill persons with debilitating conditions are particularly prone to poor physical vitality and development. The health status of disabled individuals is dependent upon a variety of variables including socioeconomic level, disability, and geographic location. Fait and Dunn (1984) reported that generally disabled students have a history of high caloric intake, poor eating habits, and low protein supplements. Part of the problem lies in determining daily minimal requirements and the overall lack of activity which lends itself to a compromised overall health status. The ability of the child to maintain a daily exercise and activity program facilitates the homeostatic functions of the body enables the child to remediate obesity and other debilitating problems.

Socialization and Self Concept

The development of social skills for the developmentally disabled is an important objective of the physical education program. Social skills improve the chances of social acceptance by others (Auxter & Pyfer, 1985). Seaman and DePauw (1984) indicated that physical education is an efficient medium through which disabled children can develop those social skills necessary for interaction with non-handicapped peers. Appropriate physical education programs can help the developmentally disabled demonstrate:

1. Socially acceptable social characteristics;
2. Social acceptance in a variety of social experiences and interactions with non-handicapped peers
3. Social capabilities to peers;
4. Self contributions to team and group efforts.

The relationship between motor performance and socialization is very important to the preschool handicapped child. Efforts to seek and gain approval occur frequently for the young as they utilizes various movement patterns.

For the older handicapped child social activities may be conceptualized as consisting of various levels including unoccupied, independent, and interactive. The primary instructional focus involves the determination of the appropriate times, places and frequency associated with various isolated and cooperative activities. The social skills involved in most activities generally consist of initiating, receiving, sustaining, and terminating an activity (Snell, 1980).

Activities such as a quality physical education program can facilitate the process of developing appropriate social skills by virtue of the structure and activities that are presented in the curriculum. By facilitating social skill development, a quality physical education program plays a significant role in helping the developmentally disabled to overcome barriers in transition, employment and recreation.

Work Performance

Transition to adulthood, success on the work force, and competitive employment are affirmative phrases which describes succinctly the goal and aims of education for the disabled. For the client to be successful, certain skills and abilities need to be developed and maintained. Work skills, socialization, and health are three leading factors that contribute to success on the work force. A quality physical education program directly contributes to a client's ability to develop these skills.

Competitive employment for the disabled usually includes job skills that focus upon some form of manual dexterity including gross and fine motor skills. Common competitive employment opportunities include janitorial work, fast food positions, and unskilled labor positions. Each of these typical employment opportunities requires if not demands the clients to demonstrate proficiencies in fine motor skills, strength, endurance, perceptual-motor skills, and other gross motor skills.

Effective work skills require the disabled to respond to a changing work requirement and to enjoy meaningful and fulfilling vocational performance. Appropriate physical education programs can help the handicapped to achieve success on the work force. Successful performance requires the worker to have at least adequate sensorimotor, leisure and recreational skills (Crosson, 1978 and Zigmond & Brownlee, 1981).

Additionally, interaction with non-handicapped peers is usually cited as one of the leading factors for failure on the

Developmentally Disabled

National Consortium on Physical Education and Recreation for the Handicapped

Part II

Statutory Revision of the Developmental Disabilities Act
(PL 98-527)
March 31, 1987

It is the expressed position of the National Consortium on Physical Education and Recreation for the Handicapped that the Developmental Disabilities Act assist States in assuring that persons with developmental disabilities receive the care, treatment, and other services necessary to enable them to achieve their maximum potential through increased independence, productivity, and intergration in the community. It is the opinion of the NCPERH that appropriate physical education and recreation activities enables the developmentally disabled to develop specific psychomotor and leisure skills which will facilitate the transitional process and enable persons with developmental disabilities to achieve their maximum independence. The President's Commission on Americans Outdoor has recommended that a significant amount of funds be set aside to improve outdoor leisure opportunities for the disabled.

In keeping with the spirit and intent of the Developmental Disabilities Act, the National Consortium on Physical Education and Recreation for the Handicapped proposes the following inclusions to the Act:

GENERAL:

That the statutes allow for the development and implementation of model and/or demonstration centers in the area job. Leisure and recreational activities are common means by which employees develop interpersonal contact and development. A quality physical education program prepares the client for this form of socialization. Exhibit 1 clearly shows the common physical education skills needed by clients to pursue their employment, recreational and socialization needs during the transition and post secondary period.

Summary

The need for a quality and an appropriate physical education program for the developmentally disabled has been briefly evidenced as contributing to a handicapped child's psychomotor education, health and well-being, socialization, and work performance. The development of quality physical education programs have not received the same attention and support as have other areas of special education. Evidence is presented in the next section of this testimony to support the fact that handicapped children are not receiving an appropriate physical education program and thereby are being denied their equal rights and protection under EHA and denied the opportunity to achieve a quality of life and wellbeing which a comprehensive physical education program can help to provide.

of physical education and recreation for the handicapped that promotes, demonstrates, and includes the developmentally disabled in programs designed to improve their indepedence within the community and during the transitional period.

SPECIFICS:

Language Defined:

To include: Means to add to the existing statutes.
To reflect: Means to insure that the Secretary and the State provides stated services and programs without statutory revision.

Part A General Provisions

Section 102: Definitions:

To include in (11)(A) of this section after sheltered employment the following phrase: "Physical Education", recreation and socialization.

To include as (viii) the following phrase, "model service and demonstration programs in physical education and recreation for the disabled."

To include in (C) of this section the phrase "physical education and recreation activities."

To reflect in (13) of this section the services of physical education and recreation programs within the University Affiliated Facilities. To insure that the State and subsequent directors of UAFs understand the need and importance of these services and establish priorities for funding within the facility or through satellite centers.

Part B Federal Assistance for Planning and Service Activitiss for

Persons with Developmental Disabilities

Section 122: State Plans

To reflect in 2(C) of this section: To determine the need and resources available in the area of physical education and recreation for the disabled. That the State insures that the extent and scope of physical education and recreation services be identified ,reported, and disseminated.

Part D- University Affiliated Facilities

Section 152: Grant Authority

To reflect in (2) the provision of service related training to include physical education and recreation personnel.

To include in (3) the conducting of applied research programs in the area of physical education and recreation for the disabled.

Part E Special Projects

Section 162: Grant authority

To include as (D) the following: Demonstration projects (including research, training, and evaluation) and technical assistance in the area of physical education and recreation for the disabled .

ASHA American Speech-Language-Hearing Association
10801 Rockville Pike • Rockville, Maryland 20852 • (301) 897-5700 (Voice or TTY)

April 20, 1987

The Honorable Tom Harkin
Chairman
Subcommittee on the Handicapped
Committee on Labor and Human Resources
113 Senate Hart Office Building
Washington, D.C. 20510

Attention: Robert Silverstein

Dear Senator Harkin:

On behalf of the American Speech-Language-Hearing Association (ASHA), I am pleased to submit a statement of our views and recommendations related to the Developmental Disabilities Act. I would appreciate having this statement included in the Subcommittee's record on reauthorization of the Act.

Please let me know if you or your staff have any questions or would like additional information.

Sincerely,

Roger P. Kingsley

Roger P. Kingsley, Ph.D.
Director
Congressional Relations Division

cc: Members of Subcommittee on
the Handicapped

Bill Jones and Al Guida
AAUAP

AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

Statement on

READTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ACT

SENATE COMMITTEE ON LABOR AND HUMAN RESOURCES

SUBCOMMITTEE ON THE HANDICAPPED

Submitted by

ROGER P. KINGSLEY, Ph.D.

DIRECTOR, CONGRESSIONAL RELATIONS DIVISION
GOVERNMENTAL AFFAIRS DEPARTMENT
AMERICAN SPEECH-LANGUAGE-HEARING ASSOCIATION

April 8, 1987

10801 Rockville Pike, Rockville, Maryland 20852 (301) 897-5700

As the professional and scientific association representing 52,000 speech-language pathologists and audiologists nationwide, the American Speech-Language-Hearing Association (ASHA) is very concerned about the adequacy of services to infants and young children with disabilities. We are pleased that, as part of the reauthorization of the Developmental Disabilities Act, the Subcommittee is examining the problems of adequate health care, rehabilitation, and special education and related services among infants and young children with serious disabilities. As a result of the new mandate in P.L. 99-457 to serve children five years and under, the issue of adequate numbers of qualified personnel must be addressed.

Provisions in the Laws for Speech-Language Pathology and Audiology Services

Both the Developmental Disabilities Act and the Education of the Handicapped Act contain provisions for the training of personnel to serve individuals with disabilities.

Among the purposes of the Developmental Disabilities Act (Part A, 101 (c) and (d)) is

> "...to train professional and paraprofessional personnel with respect to providing services to persons with developmental disabilities;" and "to make grants to university affiliated facilities to assist them in administering and operating demonstration facilities for the provision of services to persons with developmental disabilities and interdisciplinary training programs for personnel needed to provide specialized services for these persons."

The DD Act also provides for service activities (Section 102 (11)(B)) for

> "the training of personnel, including parents of persons with developmental disabilities, professionals, and volunteers, to provide services..."

University affiliated facilities are public or nonprofit facilities which are associated with colleges or universities and which provide for activities including (Section 102 (13)(A))

> "Interdisciplinary training for personnel concerned with developmental disabilities which is conducted at the facility and through outreach activities."

Both laws recognize the prevalence of children with speech, language, and hearing disorders and the need to provide services to this population. The definition of developmental disabilities (Part A, Section 102 (7)(D)) refers in part to

> "substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction (vi) capacity for independent living, and (vii) economic self sufficiency."

Clearly, a major purpose of the Developmental Disabilities Act is to provide services to people with disabilities, including disorders of communication, by appropriately trained personnel. Last year, Congress addressed the "urgent and substantial need" for early intervention services to children ages birth through two who have or are at the risk of developing (at the state's discretion) disabilities. The purposes of the new program are:

> "(1) to enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay, (2) to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after handicapped infants and toddlers reach school age, (3) to minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society, and (4) to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps."

The Education of the Handicapped Act Amendments of 1986 (P.L. 99-457) includes in the definitions of "handicapped infants and toddlers" and "early in "(i) physical development, (ii) cognitive development, (iii) language and speech development, (iv) psycho-social development..." all of which relate to communication disorders. Among the specific services that must be provided under Section 672 (2) (E) are "(iii) speech pathology and audiology." And, these services are (F) [to be] "provided by qualified personnel, including -- (i) special educators, (ii) speech and language pathologists and audiologists..." P.L. 99-457 also includes a provision for Part H (Section 676 (b)(14)) and an amendment to Part B -- Basic State Grants for the Education of All Handicapped Children -- (Section 613 (a)(13)) which requires that states ensure that personnel meet the highest standard for qualification to practice in a particular professional discipline. The purpose of this amendment was to require states that permit the use of emergency or temporary credentials or that allow a lesser professional standard for school-based personnel to reform these practices in a manner that will guarantee that children with disabilities receive the same quality services available to people under other public programs.

Communication Disorders in the Early Childhood Population

The Department of Education reported that during the 1984-85 school year there were 4,363,031 handicapped children served under P.L. 94-142 and P.L. 89-313.[1] During this same period there were 259,483 preschool-age children served.[2] While a majority of children in the 3 through 5 age group are presently receiving special education and related services, P.L. 99-457 expands the Preschool Grant Program so that by the early 1990's, all preschool-age children with disabilities will be served.

Children with speech or language impairments represent the second largest category of handicapped children, with 1,129,417 children served during the 1984-85 school year:[3] The Department of Education reports that while the number of speech or language impaired children in the 6-21 age range is declining, there has been a concurrent increase in the number of 3-5 year olds with such disorders. With the preschool population growing at a faster rate than the general school-age population, the Department predicts an increase in the number of young children with communication disorders in the coming years.[4]

The vast majority of preschool-age children served (70.5 percent) had a primary handicap of speech or language impairment.[5] This does not include the large number of children with other primary handicaps (e.g., mental retardation, cerebral palsy, learning disability, hearing impairment, multiple handicaps) who have concomitant speech or language disorders.

Because services to children with disabilities below the age of three have been available in some states and in some programs but not others, few data exist on the overall prevalence of children served and unserved in this age group. We do know, however, that there is a substantial need for services to children ages birth through five who have communication disorders. A 1986 ASHA survey found that children ages 0-5, inclusive, comprised 26.8 percent of the caseloads of speech-language pathologists and 25.1 percent of the caseloads of audiologists.[6]

As more is learned about the causes of serious physical and mental disabilities, strategies can be developed for reducing the incidence of such disabilities in newborns. However, this nation has only begun to deal with problems like congenital defects and low birth weight that are often the cause of mental retardation, autism, deafness, cleft palate and other conditions with associated speech, language and hearing disorders. At the same time as progress is made in alleviating disease and disability in some areas (for instance through family planning, accident prevention, and infant screening), new problems arise in other areas (like infants born with diseases and disabilities resulting from maternal use of drugs and/or alcohol and AIDS). Between 100,000 and 150,000 children with congenital anomalies which result in mental retardation are born each year (3-5 percent of all newborns). Many of these children have additional disabilities and another 1-2 percent of infants are born annually with just physical disabilities.[7] A 1983 study found that a significant number of infants, toddlers and preschoolers were hospitalized primarily as a result of a disease of the nervous system and sense organs (including communication disorders) -- 16.7 per 1,000 children under one year old and 9.7 per 1,000 children ages 1 to 4.[8] Included in the list of most common diagnoses in the Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program are hearing impairments in young children.[9]

Early Intervention Personnel Needs

With a high prevalence of very young children with disabilities, including disorders of speech, language and hearing, and a broad new national mandate for serving these children, it is imperative that adequate numbers of qualified personnel are trained and available to provide necessary services. The Department of Education reports that the number of special education teachers has risen annually since the implementation of P.L. 94-142 began in 1976. However, the Department also found that 17,103 additional special education teachers were needed and that there were particular shortages of personnel in several areas including multihandicapped, hard-of-hearing and deaf.[10] The personnel problem is more serious than the figures indicate because they do not take into account the number of special education personnel who are unqualified or underqualified to serve children with particular kinds of disabilities.

The authors of a major study of special education personnel stated that

> "When supplies of any resource are plentiful, the tendency is to sort and select the superior; when supplies are scant, one settles for less. In special education, the most widespread solution to problems of personnel shortages and recruitment problems is the issuance of certificates to persons who do not demonstrate the preparation, experience, qualifications, and other criteria ordinarily used for certification..."These same (certification) policies also make it possible for districts to increase the supply of personnel by assigning to special education those individuals who are neither prepared, qualified, nor certified to work with handicapped students."[11]

The study also reported that

> Undersupplies of personnel in speech/language/communication... present themselves a serious national needs."[12]

Recommendation

Speech-language pathologists and audiologists are qualified by their education and training to serve young children with communication disorders. These qualifications include a master's degree and a year of supervised clinical experience. Much of the clinical practicum is in university speech-language-hearing clinics and is with infants and preschoolers because these are the groups that have not previously been served in the schools in many states. Hence, the ability of speech-language pathologists to provide services to the 0-5 population is demonstrated by the academic training and clinical experience of persons who hold national certification and/or state licensure.

Although the vast majority of certified speech-language pathologists and audiologists provide services exclusively to children or work with children and adults, only two percent provide services to children in the 0-2 age range and 15 percent serve children ages 3-5.[13] In order for the states to meet the early intervention needs of children, more support for personnel training is needed. ASHA supports the initiative of the American Association of University Affiliated Programs (AAUAP) in recommending $1 million to provide support for the development and implementation of training projects in university affiliated facilities under the Developmental Disabilities Act. These projects would be targeted at interdisciplinary training of personnel to provide early intervention services. Although the bulk of personnel preparation will continue to be supported through Part D of the Education of the Handicapped Act, we believe that existing authorization levels cannot adequately meet the service and personnel needs that presently exist and that will grow as states plan and implement services to the 0-5 population. We suggest that additional training must take into account the new mandate for qualified professionals and that it must address areas of particular need with respect to the current lack of qualified providers of special education, health and related services.

Notes

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3. U.S. Dept. of Ed., p. 8.

4. U.S. Dept. of Ed., p. 8.

5. U.S. Dept. of Ed., p. 16.

6. American Speech-Language-Hearing Association, Omnibus survey (1986).

7. U.S. Department of Health and Human Services, Report to the President. Mental Retardation: Prevention Strategies that Work (1980), p. 3. (Because of differing definitions and reporting methods, no firm figure can be given, so a range is used).

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TESTIMONY
ON THE
DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

By

Eunice Kennedy Shriver
Executive Vice President
The Joseph P. Kennedy, Jr. Foundation

1987

SENATOR HARKIN, I WANT TO TAKE THIS OPPORTUNITY TO CONGRATULATE YOU ON BECOMING THE CHAIRMAN OF THE SUBCOMMITTEE ON THE HANDICAPPED OF THE SENATE LABOR AND HUMAN RESOURCES COMMITTEE. THIS IS AN IMPORTANT COMMITTEE THAT HAS CONTRIBUTED A GREAT DEAL TO IMPROVING THE LIVES OF OUR CITIZENS WHO ARE RETARDED AND DEVELOPMENTALLY DISABLED. BECAUSE OF YOUR INTEREST IN INDIVIDUALS WITH HANDICAPS, I AM CERTAIN THAT YOU WILL CONTINUE THE FINE TRADITION OF FORMER CHAIRMEN WEICKER. I OFFER YOU MY SUPPORT AND INVITE YOU TO CALL UPON ME FOR ASSISTANCE.

I ALSO WANT TO COMMEND SENATOR WEICKER FOR HIS SIX YEARS OF EXCELLENCE AS CHAIRMAN. HIS DEDICATION AND COMMITMENT TO THE NEEDS OF INDIVIDUALS WHO ARE MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED IS KNOWN NATIONWIDE. HE HAS WORKED, AND I KNOW HE WILL CONTINUE TO WORK, TO FACILITATE THE GROWTH AND DEVELOPMENT OF THESE INDIVIDUALS AND TO PROMOTE THE EXPANSION AND IMPROVEMENT OF SERVICE SYSTEMS TO MEET THEIR UNIQUE NEEDS.

IN MY COMMENTS ON THE 1987 REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT, I WILL REVIEW A NUMBER OF ISSUES, BUT I WANT TO FOCUS ON ONE PARTICULAR GROUP OF INDIVIDUALS, THOSE WHO ARE ELDERLY AND ALSO MENTALLY RETARDED OR DEVELOPMENTALLY DISABLED.

THE FIRST REASON FOR THIS FOCUS IS THAT THIS GROUP CURRENTLY INCLUDES BETWEEN 200,000 AND 500,000 INDIVIDUALS. THIS POPULATION IS EXPECTED TO GROW IN PARALLEL WITH THE GROWTH OF THE REST OF THE ELDERLY POPULATION DURING THE REMAINDER OF THIS CENTURY AND INTO THE EARLY PART OF THE NEXT CENTURY.

SECONDLY, INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED HAVE BEEN OF CONCERN TO THE JOSEPH P. KENNEDY, JR. FOUNDATION FOR MANY YEARS. WE HAVE SPONSORED DEMONSTRATION PROJECTS THROUGHOUT THE COUNTRY, AND I BELIEVE THAT THE RESULTS OF THESE PROJECTS HAVE POLICY IMPLICATIONS PERTINENT TO THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT.

HISTORICAL PERSPECTIVE ON INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED

IN ORDER TO UNDERSTAND THE CURRENT NEEDS OF THE POPULATION OF INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED, WE FIRST NEED TO UNDERSTAND SOME OF THE HISTORY RELATED TO THIS POPULATION.

IN THE FIRST 60-70 YEARS OF THIS CENTURY, MOST PARENTS WITH A CHILD WHO WAS MENTALLY RETARDED HAD TWO CHOICES. EITHER THEY COULD SEND THEIR CHILD TO A STATE INSTITUTION -- THE WILLOWBROOKS AND PENNHURSTS OF THIS COUNTRY; OR THEY COULD KEEP THEIR CHILD HOME WITH VIRTUALLY NO HELP FROM ANY GOVERNMENT AGENCY OR EVEN THEIR FRIENDS.

PRIOR TO 1975, WHEN PL 94-142 (THE EDUCATION OF ALL HANDICAPPED CHILDREN ACT) WAS PASSED WHICH REQUIRED STATES TO PROVIDE A FREE AND APPROPRIATE PUBLIC EDUCATION TO ALL HANDICAPPED CHILDREN, A HIGH PROPORTION OF CHILDREN WITH MENTAL RETARDATION WERE EXCLUDED FROM SCHOOL. IF, FOR EXAMPLE, A CHILD SHOWED SOME DIFFICULTY IN KINDERGARTEN OR THE PRIMARY GRADES, AN IQ TEST WOULD BE ADMINISTERED. IF THE CHILD SCORED BELOW 50 ON THIS TEST, THE PARENTS WOULD BE ADVISED THAT THE CHILD WAS EXEMPT FROM THE COMPULSORY SCHOOL ATTENDANCE LAWS AND, MOREOVER, THAT THERE WERE NO SCHOOL PROGRAMS TO MEET THE CHILD'S NEEDS. THEREFORE, PARENTS KEPT THEIR CHILDREN AT HOME, WHERE THEY REMAINED TOTALLY UNKNOWN TO THE SERVICE SYSTEM THAT SUBSEQUENTLY DEVELOPED.

AS A RESULT OF PARENTAL ACTION IN THE 1950'S AND 60'S, CLASS ACTION LAW SUITS IN THE 60'S AND 70'S AND MUCH STATE AND FEDERAL LEGISLATION, MANY INDIVIDUALS WHO ARE MENTALLY RETARDED AND WERE IN INSTITUTIONS, HAVE BEEN RETURNED TO THEIR FAMILIES, MOVED INTO GROUP HOMES, OR, UNFORTUNATELY, PLACED IN NURSING HOMES THAT ARE NOT PREPARED TO WORK WITH PEOPLE WHO ARE OLD AND MENTALLY RETARDED. CONCURRENTLY, SERVICE SYSTEMS HAVE DEVELOPED FOR YOUNGER INDIVIDUALS, AND IT HAS BECOME OBVIOUS THAT INTEGRATING INDIVIDUALS WITH MENTAL RETARDATION INTO APPROPRIATE COMMUNITY ENVIRONMENTS IS ONE OF THE BEST WAYS TO MEET THE NEEDS OF THE MAJORITY OF INDIVIDUALS WITH MENTAL RETARDATION.

THE NATION IS NOW CONFRONTED WITH TWO POPULATIONS OF ELDERLY INDIVIDUALS WHO ARE MENTALLY RETARDED. THE FIRST IS COMPOSED OF THOSE WHO HAVE BEEN AT HOME WITH THEIR PARENTS FOR ALL OF THEIR LIVES. THE SECOND IS THOSE WHO WERE IN INSTITUTIONS AND WHO HAVE SUBSEQUENTLY BEEN "DEINSTITUTIONALIZED."

THE SCOPE OF THE PROBLEM OF INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED

GETTING ACCURATE COUNTS OF THE NUMBER OF INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED IS DIFFICULT. ESTIMATES RANGE FROM 200,000 TO 500,000 INDIVIDUALS WHO ARE 60 AN OLDER AND WHO ARE DEVELOPMENTALLY DISABLED. THE MAJORITY OF THESE INDIVIDUALS ARE MENTALLY RETARDED.

TO LOOK AT THIS ISSUE ANOTHER WAY AND TO EMPHASIZE HOW MANY OF THESE INDIVIDUALS MAY BE UNKNOWN TO THE SERVICE SYSTEM, LET ME REVIEW SOME OF THE DATA THAT HAVE BEEN COLLECTED IN TWO COUNTIES IN OHIO WHERE ONE OF THE KENNEDY FOUNDATION PROJECTS OPERATE. IN STARK COUNTY, OHIO WITH AN OVER-60 POPULATION OF 60,000, THERE ARE SOME 900 INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED. YET, THERE ARE ONLY 65 OF THESE INDIVIDUALS IN THE COUNTY BOARD OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES PROGRAMS. IN SUMMIT COUNTY, OHIO WITH AN OVER-60 POPULATION OF 84,000, THERE ARE SOME 1200 INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED; BUT ONLY 140 ARE IN COUNTY BOARD PROGRAMS.

IN ANOTHER STUDY, IN NORTHEAST OHIO, DATA WERE COLLECTED ON THE CHARACTERISTICS AND LIFE STATUS OF 97 PERSONS WHO ARE MENTALLY RETARDED OR DEVELOPMENTALLY DISABLED AND OVER-60. THREE-FOURTHS WERE MODERATELY TO MILDLY RETARDED, I.E., NEEDING SOME SUPERVISION IN DAILY ACTIVITIES. GENERALLY, THESE INDIVIDUALS WERE ABLE TO COMMUNICATE, WERE FREE OF MALADAPTIVE BEHAVIORS AND HAD PHYSICAL HEALTH STATUS COMPARABLE TO SIMILARLY AGED INDIVIDUALS IN THE GENERAL POPULATION. THEIR ACADEMIC AND SOCIAL SKILLS WERE LIMITED AND, IN GENERAL, THEY DID NOT USE COMMUNITY SERVICES AVAILABLE TO OLDER ADULTS. IN THE POPULATION STUDIED, ABOUT THREE-FOURTHS LIVED IN GROUP HOMES OR NURSING HOMES, AND THE REMAINDER LIVED WITH THEIR FAMILIES OR ALONE.

DEMONSTRATION PROJECTS SPONSORED BY THE JOSEPH P. KENNEDY, JR. FOUNDATION TO MEET THE NEEDS OF INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED

THE JOSEPH P. KENNEDY, JR. FOUNDATION HAS SUPPORTED SEVERAL DEMONSTRATION PROJECTS TO SHOW HOW THE NEEDS OF INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED OR DEVELOPMENTALLY DISABLED CAN BE SERVED EFFECTIVELY AND ECONOMICALLY.

EACH OF THESE KENNEDY FOUNDATION PROJECTS SEEK TO SHOW HOW INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED CAN BE SERVED BY THE SYSTEM OF SERVICES FOR AGING INDIVIDUALS WHO ARE NOT MENTALLY RETARDED. WE RESPECT THE RIGHT OF PERSONS WHO ARE OLDER AND RETARDED TO RETIRE, TO ENJOY MORE LEISURE

OPTIONS, TO MAKE CHOICES ABOUT THEIR OWN LIVES, AND TO SPEND THEIR LATER YEARS WITH A SENSE OF DIGNITY AND ACCOMPLISHMENT.

THE FIRST PROJECT IS THE KENNEDY ACCESS PROJECT LOCATED AT THE UNIVERSITY OF AKRON IN AKRON, OHIO. THE PROJECT IS DIRECTED BY RUTH ROBERTS, PH.D., AN ENERGETIC SEPTUAGENARIAN WITH AN EXTENSIVE BACKGROUND IN THE MENTAL RETARDATION FIELD. SHE IS ABLY ASSISTED BY MARION STROUD, PH.D., A SPECIALIST IN MENTAL RETARDATION AND EVELYN SUTTON, A GERONTOLOGIST.

THE ACCESS PROJECT HAS DEVELOPED A SYSTEM OF MATCHING ELDERLY INDIVIDUALS WITHOUT HANDICAPS WITH ELDERLY INDIVIDUALS WHO ARE MENTALLY RETARDED. THE NON-HANDICAPPED INDIVIDUALS ASSIST THEIR "FRIENDS" IN MANY WAYS. THESE INCLUDE INTRODUCING THE INDIVIDUAL WITH MENTAL RETARDATION TO COMMUNITY ACTIVITIES SUCH AS NUTRITION CENTERS FOR ELDERS AND SENIOR CENTER PROGRAMS. THEY ALSO, BY BECOMING PERSONALLY INVOLVED WITH THEIR FRIENDS, INCREASE THE COMUNICATION AND SOCIAL SKILLS OF THE INDIVIDUAL WITH MENTAL RETARDATION. SOME OF THE ACTIVITIES OF THE ACCESS PROGRAM HAVE BEEN CARRIED OUT USING PROGRAMS FUNDED BY AREA OFFICES ON AGING THROUGH THE OLDER AMERICANS ACT.

IN APPENDIX IV I HAVE INCLUDED STATISTICAL INFORMATION REGARDING THE CLIENTS IN THE ACCESS PROJECT. WHAT IMPACT HAS THE ACCESS PROJECT HAD? AT A PERSONAL LEVEL, PERSONS WITH

MENTAL RETARDATION HAVE CHANGED FROM BEING PASSIVE AND UNEMOTIONAL TO BEING ACTIVE AND INVOLVED.

-- ONE WOMAN, WHO DISLIKED GOING ANYPLACE WHERE SHE HAD TO TALK TO STRANGERS, NOW ACCOMPANIES A VOLUNTEER TO DELIVER MEALS-ON-WHEELS AND ENGAGES IN CONVERSATION TO MAKE THE VISIT MORE ENRICHING FOR ALL INVOLVED.

-- ANOTHER WOMAN IS WELCOMED INTO A SINGING GROUP THAT PROVIDES ENTERTAINMENT IN NURSING HOMES.

-- ONE MAN IS A MEMBER OF AN ORAL HISTORY GROUP.

-- SEVERAL OF OUR SENIORS WITH MENTAL RETARDATION HELP OUT AT THE NUTRITION CENTERS THEY ATTEND BY SETTING AND CLEARING TABLES.

-- A WOMAN WHO LOVES TO CLEAN IS GOING WITH HER VOLUNTEER FRIEND TO PROVIDE FREE CLEANING SERVICES TO A PHYSICALLY INCAPACITATED PERSON.

-- A WOMAN HAD A PIECE OF HER ART WORK SELECTED FOR A SHOW AT THE AKRON ART INSTITUTE.

THESE INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED ARE MAKING SIGNIFICANT CONTRIBUTIONS TO THEIR COMMUNITY. EVEN THE BUS DRIVERS COMMENT ON THE CHANGES THEY ARE SEEING IN THE CLIENTS FROM THE ACCESS PROJECT.

AS INDIVIDUALS WITH MENTAL RETARDATION AGE, NOT ONLY DO THEY NEED MORE AND MORE HELP FROM SERVICE SYSTEMS, BUT PERSONNEL IN THE SERVICE SYSTEMS NEED TO BE PREPARED TO PROVIDE FOR THESE NEW CLIENTS. THE KENNEDY FOUNDATION IS SPONSORING A CROSS-DISCIPLINARY TRAINING PROJECT AT THE UNIVERSITY CENTER ON AGING AT THE UNIVERSITY OF MASSACHUSETTS MEDICAL CENTER IN

ON AGING AT THE UNIVERSITY OF MASSACHUSETTS MEDICAL CENTER IN WORCESTER, MASSACHUSETTS. IN THIS PROGRAM, DIRECTED BY ROSALIE WOLF, PH.D., MEDICAL STUDENTS AND FAMILY PRACTICE RESIDENTS ARE GIVEN TRAINING IN THE HEALTH CARE NEEDS OF ELDERLY INDIVIDUALS WHO ARE MENTALLY RETARDED; AND STUDENTS IN THE BACCALAUREATE CERTIFICATE PROGRAM IN GERONTOLOGY ARE TAUGHT ABOUT THE NEEDS OF ELDERS WITH DEVELOPMENTAL DISABILITIES.

AT THE SHRIVER CENTER IN WALTHAM, MASSACHUSETTS A MODEL SYSTEM HAS BEEN DEVELOPED BY MARY HOWELL, M.D., PH.D., THAT DELIVERS SOME OF THE SPECIALIZED SERVICES REQUIRED BY INDIVIDUALS WHO ARE ELDERLY AND MENTALLY RETARDED AND THAT PROVIDES TRAINING FOR PROFESSIONALS WHO WILL WORK IN THE AGING AND DEVELOPMENTAL DISABILITIES SYSTEMS. PATIENTS ARE SEEN FOR A MULTI-PHASIC HEALTH AND SOCIAL ASSESSMENT WHICH INCLUDES: MEDICINE, NURSING, SOCIAL WORK, COMMUNITY MENTAL HEALTH, CLINICAL PSYCHOLOGY, LAW, SPORTS AND THERAPEUTIC RECREATION, COMMUNITY RESOURCES AND MINISTRY.

GRADUATE STUDENTS FROM ALL OF THESE DISCIPLINES ARE INVOLVED IN THIS ACTIVITY. AS A RESULT, THERE ARE NOW SOME INDIVIDUALS IN EACH OF THESE AREAS WITH FORMAL TRAINING REGARDING THE NEEDS OF OLDER INDIVIDUALS WHO ARE MENTALITY RETARDED. THESE GRADUATE STUDENTS HAVE ALSO PERFORMED VALUABLE RESEARCH IN AREAS AS DIVERSE AS "AN ASSESSMENT OF HEALTH CARE NEEDS OF CLIENTS WITH DOWN SYNDROME AND

ALZHEIMER'S DISEASE," TO "ASSISTING CLIENTS WITH MENTAL RETARDATION TO WRITE WILLS."

MANY OLDER CITIZENS WHO ARE MENTALLY RETARDED HAVE BEEN MOVED FROM LARGE STATE INSTITUTIONS TO NURSING HOMES. WHILE THIS TYPE OF ARRANGEMENT MAY BE NECESSARY IN CERTAIN CASES, THIS TYPE OF PLACEMENT OFTEN OCCURS BECAUSE THERE IS NO COMMUNITY LIVING ARRANGEMENTS AVAILABLE FOR THE PERSON. THIS SITUATION MAY ALSO DEVELOP WHEN ELDERLY PARENTS OF AN AGING CITIZEN WHO IS MENTALLY RETARDED BECOME INCAPACITATED OR DIE. THE KENNEDY FOUNDATION SPONSORED FAMILY CARE PROGRAM FOR ELDERLY RETARDED PERSONS THAT HAS OPERATED OUT OF THE TRI-VALLEY ELDER SERVICES, INC. OF SOUTHBRIDGE, MASSACHUSETTS ADDRESSES THIS PROBLEM. IT MAKES ARRANGEMENTS FOR COMMUNITY-BASED FOSTER FAMILY LIVING OPPORTUNITIES FOR ELDERLY PERSONS WITH MENTAL RETARDATION. ONCE A PERSON IS PLACED WITH A FOSTER FAMILY, TRI-VALLEY PROVIDES RESPITE AND SUPPORT SERVICES. (THESE SERVICES ARE ALSO PROVIDED WHEN A PERSON WHO IS ELDERLY AND MENTALLY RETARDED LIVES WITH HIS/HER NATURAL FAMILY). TO DATE, THE PROGRAM HAS FOUND FOSTER FAMILIES FOR FORTY INDIVIDUALS. IT HAS BEEN JUDGED SO SUCCESSFUL THAT ITS FUNDING HAS BEEN TAKEN OVER BY THE MASSACHUSETTS DEPARTMENTS OF AGING AND MENTAL RETARDATION.

ON THE BASIS OF THE INFORMATION DERIVED FROM OUR VARIOUS DEMONSTRATION PROJECTS, I BELIEVE THAT SOME MINOR ALTERATIONS TO THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF

RIGHTS ACT COULD IMPROVE THE LIVES OF AMERICANS WHO ARE AGING AND RETARDED OR DEVELOPMENTALLY DISABLED. IT WOULD BE INAPPROPRIATE TO EXPECT THIS ACT TO FULLY FUND PROGRAMS SUCH AS I HAVE DESCRIBED; HOWEVER, THE ACT CAN BE AMENDED TO TAKE INTO ACCOUNT THE NEEDS OF THIS SPECIAL AND GROWING GROUP OF PEOPLE. ALSO, THE ACT SHOULD CERTAINLY SUPPORT THE TRAINING OF PROFESSIONALS AND PARAPROFESSIONALS WHO WILL SERVE OLDER CITIZENS WHO ARE RETARDED OR DEVELOPMENTALLY DISABLED.

I WILL SUMMARIZE MY RECOMMENDATIONS. DETAILS CAN BE FOUND IN APPENDIX I. I SUGGEST:

1. THAT SECTION 102(11)(D) OF PART A, TITLE I BE AMENDED TO INCLUDE ELDERLY PARENTS OF OLDER PERSONS WITH A DEVELOPMENTAL DISABILITY WITHIN THE DEFINITION OF FAMILY SUPPORT SERVICES.

2. THAT SECTION 122(b)(4) WOULD BE AMENDED TO ADD A NEW SUBSECTION (G) TO INCLUDE A PROVISION THAT INFORMATION CONTAINED IN THE STATE AGING PLAN BE CONSIDERED IN DELIBERATIONS BEFORE THE COUNCIL AND THAT THE COUNCIL UNDERTAKE EFFORTS TO PROMOTE THE ESTABLISHMENT OF AN INTERAGENCY AGREEMENT BETWEEN THE STATE AGING AGENCY AND THE STATE'S LEAD AGENCY FOR MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES. THE PURPOSE WOULD BE TO MAKE OPTIMUM USE OF THE CONJOINT RESOURCES OF THE AGING NETWORK AND THE DEVELOPMENTAL DISABILITIES SYSTEM WITH REGARD TO RESIDENTIAL ARRANGEMENTS, TRANSITIONAL SERVICES THAT BRIDGE WORK AND RETIREMENT, SPECIAL SUPPORTS TO ELDERLY PARENTS OF OLDER PERSONS WITH DEVELOPMENTAL DISABILITIES, AND OTHER SERVICES SUCH AS USE OF SENIOR CENTER ACTIVITIES AND OTHER AGING NETWORK PROGRAMS.

3. THAT SECTION 122(b)(2)(C) OF PART B, TITLE I BE AMENDED TO INCLUDE A PROVISION FOR DESCRIBING THE NEEDS OF OLDER

DEVELOPMENTALLY DISABLED PERSONS, AND THAT SECTION 124(a)(1) OF PART B, TITLE I BE AMENDED TO INCLUDE THE REPRESENTATION OF THE STATE UNIT ON AGING ON THE DEVELOPMENTAL DISABILITIES PLANNING COUNCIL.

4. THAT SECTION 152 OF PART D, TITLE I BE AMENDED TO ADD THE PROVISION FOR UNIVERSITY AFFILIATED FACILITIES, IN CONJUNCTION WITH CENTERS ON AGING, GERONTOLOGY CENTERS, AND GERIATRIC EDUCATION PROGRAMS, TO UNDERTAKE TRAINING AND EDUCATION OF PERSONNEL IN AGING AND DEVELOPMENTAL DISABILITIES.

ROBERT BROWNING WROTE, "GROW OLD ALONG WITH ME, THE BEST IS YET TO BE." BUT FOR THOUSANDS OF OLDER CITIZENS, ESPECIALLY THOSE WITH MENTAL RETARDATION, THERE IS MORE POETRY THAN TRUTH IN THIS STATEMENT. WITH SOME MINOR ALTERATIONS IN THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT, YOU CAN TRULY HELP MORE THAN ONE QUARTER MILLION ELDERLY MENTALLY RETARDED INDIVIDUALS TODAY AND MORE THAN A MILLION WITHIN FIVE YEARS. I URGE YOUR SUPPORT FOR THE LEGISLATION BEFORE YOU WITH THE CHANGES WHICH I HAVE RECOMMENDED.

THANK YOU.

APPENDIX I

Suggested Legislative Language

DISCUSSION DRAFT

SUGGESTED CHANGES TO PL 98-527 (DEVELOPMENTAL DISABILITIES ACT) TO ACCOMMODATE NEEDS OF GROWING POPULATION OF OLDER DEVELOPMENTALLY DISABLED PERSONS

CHANGES TO PART A

1. That Section 102(11)(D) of Part A, Title I be amended to include elderly parents of older persons with a developmental disability within the definition of family support services.

The amendment to Section 102(11)(D) would read as follows:

"(D) The term 'alternative community living arrangement services' means such services as will assist persons with developmental disabilities in developing or maintaining suitable residential arrangements in the community, including in-house services (such as personal aides and attendants and other domestic assistance and supportive services), family support services (including services to elderly parents), foster care services, group living services, respite care, recreation and socialization services, and staff training, placement, and maintenance services.

CHANGES TO PART B

1. That Section 122(b)(4) would be amended to add a new subsection (G) to include a provision that information contained in the state aging plan be considered in deliberations before the Council and that the Council undertake efforts to promote the establishment of an interagency agreement between the state aging agency and the state's lead agency for mental retardation/developmental disabilities. The purpose would be to make optimum use of the conjoint resources of the aging network and the developmental disabilities system with regard to residential arrangements, transitional services that bridge work and retirement, special supports to elderly parents of older persons with developmental disabilities, and other services such as use of senior center activities and other aging network programs.

The amendment to Section 122(b)(4) would read as follows:

"(G)(i) The plan must be developed after consideration of information developed by the State's unit on aging under Section 307(a) of the Older Americans Act.

"(ii) The plan must provide that interagency agreements will be initiated between the State's unit on aging and the State's principal agency serving adults with developmental disabilities relative to conjoint planning and service.

coordination, with particular respect to provision of family support services, residential arrangements, community activity services, and supports to retirement activities.

2. That Section 122(b)(2)(C) of Part B, Title I be amended to include a provision for describing the needs of older developmentally disabled persons, and that Section 124(a)(1) of Part B, Title I be amended to include the representation of the state unit on aging on the developmental disabilities planning council.

The amendment to Section 122(b)(2)(C) would read as follows:

"(C) describe (and provide for the review annually and revision of the description not less often than once every three years) (i) the extent and scope of services being provided, or to be provided, to persons with developmental disabilities under such other State plans for federally assisted State programs as the State conducts relating to education for the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, crippled children's services, aging, and comprehensive health and mental health, and under such other plans as the Secretary may specify, and (ii) how funds are allotted to the State in accordance with section 125 will be used to complement and augment rather than duplicate or replace services for persons with developmental disabilities who are eligible for Federal assistance under such other State programs;

The amendment to Section 124(a)(1) would read as follows:

"SEC. 124.(a)(1) Each State which receives assistance under this part shall establish a State Planning Council which will serve as an advocate for persons with developmental disabilities. The members of the State Planning Council of a State shall be appointed by the Governor of the State from among the residents of that State. The Governor of each State shall make appropriate provisions for the rotation of membership on the Council of that State. Each State Planning Council shall at all times include in its membership representatives of the principal State agencies (including the State agency that administers funds provided under the Rehabilitation Act of [1973] 1986, the State agency that administers funds under the Education of the Handicapped Act, the State agency that administers funds provided under the Older Americans Act, the State agency that administers funds under Title XIX of the Social Security Act for persons with developmental disabilities), higher education training facilities, each university affiliated facility or satellite center in the State, the State protection and advocacy system established under section 142, local agencies, and nongovernmental agencies and private nonprofit groups concerned with services to persons with developmental disabilities in that State.

CHANGES TO PART D

1. That Section 152 of Part D, Title I be amended to add the provision for university affiliated facilities, in conjunction with centers on aging, gerontology centers, and geriatric education programs, to undertake training and education of personnel in aging and developmental disabilities.

It is proposed that Section 152 of Part D, Title I be amended by adding new subsections (e) and (f). The amendment would read as follows:

"(e)(1) The Secretary shall make grants to colleges and universities to support development and operation of at least 10 regionally distributed university affiliated facilities which shall offer graduate-level educational programs providing interdisciplinary training to professionals to enable them to provide services to increase or maintain the independence, productivity, health and well-being, and integration into the community of elderly persons with developmental disabilities.

"(2) To be eligible for a grant under this subsection, a college or university shall--

"(A) at the time of applying for such a grant, offer graduate-level training in a field concerned with providing for the needs of persons with developmental disabilities or elderly persons, which may include gerontology or geriatric medicine; and

"(B) formulate and propose a program of study that will provide training in a variety of fields related to the needs of elderly persons with developmental disabilities.

"(3) A grant may be made under this subsection to fund a program proposed to be operated jointly by two or more different universities located in the same region.

"(f)(1) For the purpose of making grants under subsection (e) of section 152, there are authorized to be appropriated $1,167,000 for each of the fiscal years 1988, 1989, and 1990.

"(2) Funds appropriated under this section are available until expended.

APPENDIX II

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APPENDIX III

Comments On Other Aspects of the Developmental Disabilities Assistance and Bill of Rights Act

RECOMMENDATIONS REGARDING THE REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

PROGRAMS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

PART A - GENERAL PROVISIONS

DEFINITIONS (Section 102)

ISSUE 1 : There are many activities which do not fit into the four federal priority areas and thus, if critical to the development of a comprehensive system of community services, must be described in terms of one or the other of the four priority areas or not done. The four federal priority areas are not mutually exclusive and by no means cover all possible activities needed on the state level for persons with developmental disabilities. Changes in the language authorizing a state optional priority during the last reauthorization have precluded using the state option as a vehicle for such activities in most states. For future policy purposes and for monitoring of the program, a full reinstatement and redefinition of the state priority area is needed. The states which have selected state priorities in the past have done so for very explicit reasons and their activities frequently indicate innovative activities which are helpful in planning future reauthorizations of the Act. Most states are now precluded from continuing those efforts. Several states have used their state option to stimulate, develop, maintain and/or train state-wide networks which can assist in implementing state plan objectives for policy change on the state and local levels. People in these networks, parents, professionals, people with disabilities and others, need to be trained and supported in policy and service issues. This capacity-building activity clearly supports the role of the DD Council as advocate described in the Act and represents the kind of activity intended by Congress to achieve the law's purposes.

People with developmental disabilities also have needs that are structural in nature, i.e., services or activities that must undergird a state's system, such as the development/coordination of rural services; consumer self-advocacy; public education/awareness activities regarding developmental disabilities; transportation services to enable people in residential programs to be able to work; socio-legal and protective services; prevention activities which go beyond early childhood-related issues; the support of technological developments for people with developmental disabilities; information and referral; outreach to unserved or underserved groups; community acceptance/ organization; and other similar activities which go beyond the definition of any single federal priority area. These activities and others like them are essential to the development of a comprehensive system of services in our nation. Such innovative and successful activities do not "show up" clearly when reporting on the program and need to be monitored and shared to give direction for future federal policy and to enable states to learn from one another.

> RECOMMENDATION: The state optional priority area should be fully reinstated and its selection should be at the discretion of the states. It should not be conditional upon a demonstration that the federal priority areas are no longer needed, but upon a demonstration of the importance of such state priority activities to the development of a comprehensive array of services. A suggestion for a new definition of the optional state priority area is: "activities which effect positive change in specialized or generic services for persons with developmental disabilities, which are deemed essential by a State in achieving desired outcomes in its State Plan and/or which address two or more federal priority areas." Section 102(12)(A)(ii)

ISSUE #2: One of the most successful methods of DD Council advocacy for services is the dissemination of the results of studies of state policies which pose barriers to the independence, productivity and community integration of people with developmental disabilities. Best results in states frequently occur when the state legislature and/or Governor has been convinced by compelling facts that harmful laws should be changed or that new legislation is needed to meet identified needs. These activities need to be emphasized in the Act as service activities.

> RECOMMENDATION: Language to include "policy analysis and educating policy makers" should be added to the definition of the term "service activities." Section 102(B)(viii).

Issue #3: Support to individuals and families is a vital component of successful community living. The definition of the community living priority area does not sufficiently specify individual and family support services.

> RECOMMENDATION: Insert the words "individual and" before "family support services" in the definition of the federal priority area of community living. Section 102(D)

PART B - FEDERAL ASSISTANCE FOR PLANNING AND SERVICE ACTIVITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

STATE PLANS (Section 122)

ISSUE #1: Overwhelmingly DD Councils feel that the restriction on the number of federal priority areas a state may select is arbitrary and prevents states from clearly describing many cross-cutting and interagency initiatives in a precise way. Because the federal priority areas are very broadly defined and and inter-related and because the development of a comprehensive system of services may require the selection of all areas at any given time, the states need to be able to select up to the maximum number of federal priority areas. State Plans should continue to require that Councils indicate the percentage of funds allocated to each.

> RECOMMENDATION: Eliminate the restriction on the number of federal priority areas a state may select. Beginning in fiscal year 1988, the plan should be required to provide for at least one federal priority area and be permitted to provide for up to four federal priority areas. Section 122(b)4(B)(i)I.

Issue #2: In the 1984 reauthorization of the DD Act, a provision was added requiring that the state provide the DD Council a copy of any plans of correction for intermediate care facilities for persons with mental retardation and developmental disabilities (ICF/MR/DD) received by the state. No specific action was required, however, beyond receipt of the document(s).

> RECOMMENDATION: The DD Councils' Annual Report should describe actions taken by the State pursuant to any annual survey reports or plans of corrections for cited deficiencies prepared pursuant to section 1902(a)(31)(B) of the Social Security Act with respect to any intermediate care facilitaties for the mentally retarded/developmentally disabled in such State and should describe the response of the DD Council to such reports, plans and actions.

ISSUE #3: Demographic studies have shown that there is a need to address America's aging population. Services to elderly people who have developmental disabilities need to be planned and coordinated with services authorized by the Older Americans Act.

> RECOMMENDATION: Add the aging plan (developed pursuant to the Older Americans Act) to the list of other state plans for federally assisted state programs to be described in the DD state plan. Section 122(2)(C)(i)

PART C - PROTECTION AND ADVOCACY OF INDIVIDUAL RIGHTS

SYSTEM REQUIRED (Section 142)

ISSUE #1: Protection and Advocacy agencies, because of insufficient resources, have not adequately addressed the needs of persons with developmental disabilities who become involved in the criminal justice system.

> RECOMMENDATION: A specific focus to address the needs of persons with developmental disabilities involved in the criminal justice system should be added to the Act.

ISSUE #2: Based on the continued depopulation of state institutions and nursing homes as well as the relocation of individuals within community living arrangements, a large number of individuals are being moved with no advocacy or legal representation.

> RECOMMENDATION: Language should be included to provide the Protection and Advocacy Systems standing and representation in all situations where an individual over the age of 18, who has no family or legal guardian other than the state or county (who have potential conflicts of interest), is being considered for a change in his/her living arrangement to assure that the proposed new arrangement is appropriate to the individual's needs and that the services needed are in place or will be in place prior to such a move.

PART D - UNIVERSITY AFFILIATED PROGRAMS

ISSUE #1: There are currently 15 states (Hawaii, Alaska, Nevada, Idaho, Wyoming, North Dakota, Oklahoma, New Mexico, Arkansas, Illinois, Delaware, New Hampshire, Maine, Texas and Rhode Island) that do not have a DD-UAP. Consequently, these states suffer in at least two ways. First, there is no in-state mechanism to provide the specialized personnel preparation for the various programs that serve children and adults with developmental disabilities. Second, few - if any - programs in a state without a UAP can meet the interdisciplinary needs of "dually diagnosed" children (i.e., those youngsters with both mental retardation and some other disabling condition). In the vast majority of cases, community providers, hospitals, the State Title V Programs for Children with Special Needs (formally State Crippled Children's Services Programs) and other programs simply do not have the staff, resources and equipment necessary to provide effective services to these children.

RECOMMENDATION: Congress should make available sufficient funds to carry out a feasibility study in each state which does not now have a DD-UAP.

ISSUE #2: The demand for allied health professionals trained in the developmental disabilities field has increased, placing a substantial burden on an inadequate pool of skilled personnel. Specifically, many more trained specialists in a wide variety of fields are needed to develop the individual education and service plans (IEPs/ISPs) mandated by existing law and required for effective service delivery. There is a great need for personnel with interdisciplinary training, particularly for staff to provide services authorized by the new early intervention program in the Education of All Handicapped Children Amendments of 1986 (P.L.99-457). This program would assist states to develop and implement statewide, comprehensive, coordinated, multidisciplinary, interagency programs of early intervention services for handicapped infants and toddlers and their families (specifically infants from birth to three).

RECOMMENDATION: The authorization of $1 million to provide support for five to seven pilot development and implementation training projects (each approximately $150,000 to $200,000) through 1990. The tasks of each pilot training project will be to plan, design and implement an interdisciplinary training program to help prepare allied health professionals needed to provide early intervention services.

A standard application process administered by the Secretary should be used. A UAP prior to submitting its application, must inventory local community-level direct care and paraprofessional training programs to seek their guidance and input in the preparation of applications. Such applications would demonstrate that any UAP-provided training would be explicitly coordinated with these local programs.

GRANT/CONTRACT AUTHORITY (SECTION 162)

ISSUE 2: A major problem with the current program is that it does not fund on-going data collection activities needed to provide the nation and Congress with the information vital to policy decisions affecting people with developmental disabilities. In addition, many demonstration projects funded by Part E are inappropriate for federal funding and should, in fact, be demonstrated at the state and local levels. Such demonstrations should no longer be funded by this authority. Some of the most outstanding special projects in the past have been various policy analyses which provide needed data to enable states and the federal government to document problems and opportunities presented by state and federal policy.

In addition, the programs authorized by the Developmental Disabilites Act, the Basic State Grant Program (Councils and their Administering Agencies), Protection and Advocacy Agencies, and University Affiliated Programs have information regarding services to people with developmental disabilities that has not been collected and shared nationally. A database should be required which will be on-going, up-dated and widely available to groups, agencies and individuals. Such a database would significantly improve (1) overall program accountability (Congress and the administrative agencies could monitor the progress of all four program components to determine how well they are meeting their statutory objectives); (2) communication and sharing of information among state agencies, UAPs, DD Councils and P&As, reducing duplication of effort and receiving maximum benefit from limited resources; and (3) the ability of policy-makers to track current trends and adjust the service delivery systems. If sufficient funds are provided, the data base could collect and disseminate data from a broad range of additional programs and projects, including projects funded under this authority, forming the basis for programmatic initiatives across federal agencies. Such data collection, analysis, dissemination and data base development should be one of the major functions of this discretionary authority.

> RECOMMENDATION: $1 million should be earmarked for the on-going collection of data to be used for policy analysis and dissemination on a nationwide scale regarding policies and services affecting persons with developmental disabilities, including but not limited to activities which (a) collect and disseminate data regarding federal and state funding of services for persons with developmental disabilities under various federal and state authorities and (b) collect and disseminate data regarding the activities and effectiveness of the DD Councils, Mental Retardation/Developmental Disabilities State Agencies, the Protection and Advocacy Systems, the University Affiliated Programs and the National Policy Initiatives authority.

ISSUE 3 : Since 1983, funds authorized under this Part have been co-mingled with funds authorized by other programs of the Office of Human Development Services which provide services to Native Americans, foster and adopted children, and the aging. Requests for proposals have focused on "cross-cutting" projects which address the common needs of combinations of these populations. Since the DD Special Projects Program is small, this dilution of the focus on issues addressing the specific needs of people with developmental disabilities should be prohibited.

> RECOMMENDATION: Prohibit the inclusion of DD Special Projects funds in the Office of Human Development Coordinated Discretionary Fund.

ISSUE #3: There is increasing integration into the community of persons with developmental disabilities and, therefore, an expanding need for direct care personnel for community-based service programs. There has been a dramatic increase in the need for personnel with interdisciplinary training because of the overall expansion in badly needed community-based day and residential services to persons with developmental disabilities. Existing training programs are ill-funded and essentially ad hoc in nature. There is a need to focus a new training program to prepare hands-on, direct care personnel and paraprofessionals who are employed in community-based residential programs.

> RECOMMENDATION: Authorize the demonstration and implementation of five to ten training programs for direct care workers and paraprofessionals at a level of $1 million for FY 1988, $1 million for FY 1989 and $1 million for FY 1990.
>
> A standard application process administered by the Secretary should be used. A UAP, prior to submitting its application, must inventory local community-level direct care and paraprofessional training programs to seek their guidance and input into the preparation of the application. Any UAP provided training will be explicitly coordinated with these local programs.

ISSUE #4: Available data suggest that the number of elderly people with developmental disabilities is substantial and growing rapidly. Current national estimates indicate that there are over 200,000 individuals with severe disabilities who are 55 or older. Just 15 years from now that figure could realistically double. Our existing service and training systems are unprepared to address the needs of this burgeoning group. A major reason for the lack of appropriate services (or, in many cases no services at all) is the lack of trained personnel at all levels, from geriatricians to nutritionists.

> RECOMMENDATION: Authorize 10 UAPs to provide cross-training in the developmental disabilities field and in the aging field for geriatricians, internists, nurses, social workers and other allied health professionals. Authorize appropriations of $1.167 million per year.

PART E - SPECIAL PROJECT GRANTS

ISSUE 1: For many years, advocacy organizations have been dissatisfied and disappointed with the overall results of Special Projects funded under this authority. The needs of the developmental disabilities community for nationally significant activities are greater now than ever and, as funds for Special Projects were reduced over time, less and less has been available for the kinds of activities which provide information enabling states and federal policy makers to base decisions on facts. This authority needs to be totally restructured and carefully monitored by Congress.

> RECOMMENDATION: Re-title Part E to Nationwide Policy Initiatives to Improve Services to People with Developmental Disabilities.

PURPOSE (SECTION 161)

> RECOMMENDATION: The purpose of Part E should be "to provide funds for grants and contracts for up to five years to public and/or non-profit private agencies for initiatives which have an impact on national policy to improve services to people with developmental disabilities through: (1) data collection and dissemination; (2) technical assistance; and (3) federal interagency initiatives.

APPENDIX IV

Research Data About Kennedy Seniors in Akron Access Project

Marion Stroud

RESEARCH DATA ABOUT KENNEDY SENIORS

Data was gathered about the Kennedy Seniors in the project by using the ACCESS Assessment. This seven page instrument includes information about the demographics, physical condition, social competence, cognitive development, and use of community services. Data about the 31 Kennedy Seniors who were paired with Kennedy Companions during the first year of the grant is presented. Frequencies are reported in tables and a discussion of the most interesting aspects follows here.

Demographics (Table 1)

Women were paired with companions two to one over men. This reflects the difficult in finding male volunteers or Senior Friends more than it does the availability of mentally-retarded men who are ready to have companions. Most of the Kennedy Seniors are between the ages of 50 - 70 and are enrolled in day program at the county board of MR/DD sheltered workshops. Most live in group homes, with family or semi-independently. Their level of retardation is mild or moderate as is their adaptive behavior level. The majority are affiliated with Christian churches.

Physical Condition (Table 2)

The Kennedy Seniors are generally in good health with only the types of sensory problems expected for their age. Chronic conditions can be seen as reflecting their history of sedentary living, although most are free of continuing health problems. Almost all are of average weight, able to eat regular diets and food textures. All except two in wheelchairs can walk without assistance. More take multiple medications than would be expected from the previous finding in the ACCESS Research of 1982 (Stroud,Murphy, Roberts). The summer project conducted by Susan Keck, the medical student from N.E.O.U.C.O.M. indicated a need to investigate this multi-medication of the older adults. This will be included in future study of the population.

Social Competence

All the Kennedy Seniors except the two in wheelchairs are quite adequate in their self care skills. Personal social competence is a mixed story. Here the deprivation of training and experience can be seen in the number of adults who require assistance in the daily living skills such as telephoning, making purchases, using the bus, and finding their way around their environment. The effect of habilitation training can be observed in the greater number who are able to do simple household chores.

Interactions with others are also indicators of need for attention to training and experience in social interaction such as is provided by the grant. The full range of typical performances is found in this group. It can't be said that only those who were already socially competent were chosen to be paired with companions. The number of friends claimed by this group of older retarded adults is limited for most of them. As formerly found, there is almost a total lack of affectionate relationships.

Maladaptive behaviors are listed in rank order, with verbal aggression still seen to be the most common. Verbal aggression usually refers to name-calling and cursing. It may be the only "safety valve" for passive and powerless people. The other behaviors most commonly found tend to be passive such as withdrawal, depression, refusal to participate. Socially inappropriate behavior is one of the areas of expected change for the project. By providing same-age companions in a one-to-one relationship, it is hoped that the Senior will learn to model the socially appropriate behavior of the Kennedy Companion and other senior citizens encountered in the Senior Centers or other activities.

Leisure and Recreation

This table reflects the experiences the Kennedy Seniors reported when they were interviewed prior to being paired with companions. This will be base line data for studies of the change in choices of activity which are expected to result from the companionship program. It is hoped that many of the more interesting and stimulating activities will move from the "Never" column to "Sometimes" or "Often". Present emphasis is on television, chatting and doing household chores at home; and when going out the usual choices have been to eat out (usually at McDonalds) and to go to parties (usually the social events put on at the sheltered workshops). Church has a high preference, as was found in the 1982 study. This is an asset to be given more attention. Older adults in general are in the churches, and the possibility for linking adults with retardation to caring people in those settings is a real possibility. Those who report going to fairs and carnivals usually have been taken in van-loads to places like Sea World or Cedar Point Amusement Park.

Cognitive Development (Table 5)

The predominance of the higher functioning older adults selected to participate in the Kennedy Community Access Project reflects a desire to start out with those who were most likely to succeed in learning to expand their activities and make friends of other older adults. Thus habilitation teams recommended such clients for inclusion rather than those who had more problems. Those easiest to match with companions have been paired - now the more problematic will need to be served next year.

These older adults have few functional academic skills. Their main strength is in time telling and using calendars. They are generally unable to read programs, menus, schedules, or newspapers. Their companions need to assist them in these activities in order to prevent embarrassment. Money use is also a training need. It is in these areas that the one-to-one informal instruction is expected to be accomplished in this project.

Communication skills are near average for many of the Seniors, but they have difficulties in expressing themselves clearly. Practice in conversation with non-handicapped speakers will be provided in the companionship program, and future study will be directed to assessing the effect of practice in this "real" situation.

Use of Community Services (Table 6)

Special services for the mentally retarded population are used by almost all of the Kennedy Seniors. Medical services are required for the Individual Habilitation Plan process. Those who are participants in the county day or residential programs see doctors and dentists regularly. The use of more generic senior or community services is rare. Future re-assessment will show whether the use of generic services increases. As long as most older retarded adults have their needs met in a special service system, it is unlikely that generic services will be used unless deliberate planning for such use occurs.

More Seniors were matched with volunteers than with paid companions. The explanation for this is found elsewhere in this report.

-Marion Stroud, Ph.D.
Research and Development

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Kennedy Community Access 1986

Table 1
Demographics
Participating Kennedy Seniors

Sex

Male	11
Female	20
Total	31

Age

Age	55 - 60	5
	60 - 70	21
	70 - 85	5

Program Enrollment

CBMR/DD	28
UCP/USH	1
CYO Day	1
None	1

Residence

Semi-Independent	4
Family	7
Foster	2
Group Home	10
Nursing Home	8
Developmental Center	0

Income Source (23 cases)

Social Security	6
S.S.I.	15
Wages	17
Other	5

MR Level

Mild	10
Moderate	19
Severe	2

Guardianship

Self	23
Relative	2
APSI	6

Adaptive Behavior (23 cases)

Mild	16
Moderate	7
Severe	1

Religious Preference

Catholic	10
Protestant	13
Jewish	1
None	3

MS

Kennedy Community Access 1986

Table 2
Physical Condition

	Health			
	Average	Weak	Impaired	Disabled
general health	29		2	0
vision	16	12	3	0
hearing	21	5	5	0
teeth	14	1	4	12
limbs	27	1	1	2
joints	24	6	1	0

	Protheses			
	No need	Has, uses	Has doesn't use	Needs
eyeglasses	9	20	2	
dentures	16	11	2	2
hearing aid	26	3	1	1
cane/walker	29	2	0	0
wheelchair	29	2	0	0

Has Chronic Condition	
Heart	
Circulation	8
Seizure	6
Diabetes	1
Parkinson	0
Cancer	0
Ulcer	0
Respiratory	0
Podiatric	0

Weight	
average	18
under	3
overweight	10

Ambulation	
independent	29
wheelchair	2

Number of Medications	
none	10
one	5
two	4
three or more	12

Diet	
regular	24
reduce	8
salt free	1
sugar free	2

Food Texture	
regular	26
soft	4
chopped	1

Participating Kennedy Seniors = 31

Kennedy Community Access 1986

MS

Table 3
Social Skills

Self Care	Independent	Cued	Assisted	Unable
grooming	24	5	2	0
eating	30	1	0	0
walking	29	0	0	0
climb stairs	26	0	3	2
toileting	29	0	2	0
dressing	25	2	2	0
bathe/wash	24	6	1	0
self medicate	4/21	7/21	11/21	2/21
Personal Social				
telephone	9	9	9	4
public transportation	3	5	13	8
orientation	3	4	14	8
purchase	5	6	11	5
home care	17	11	2	1
laundry	8	9	10	3

Appropriateness of interaction	About right	Passive	Too much	With-drawn
with staff	21	7	1	2
with peers	24	5	1	1
family/relatives	20	5	1	1
professionals	18	9	1	3
strangers	18	8	2	3

Number of Friends	Many	Some	Few	None
staff	11	13	5	2
peers	8	20	2	1
family	2	10	10	9
community	2	6	9	11
affectionate	1	9	5	16

Maladaptive Behavior	Rare or never	Some	Frequent	Problematic
verbal aggression	25	4	1	1
socially inappropriate	19	9	3	0
refusal to participate	23	6	1	1
withdrawn	21	8	1	0
depressed	23	9	0	0
disoriented	20	9	2	0
anxious	24	7	0	0
wanders away	29	2	0	0
physical aggression	29	2	0	0
stealing	30	1	0	0
self injurious	30	1	0	0
destroys property	30	0	0	1

MS

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Table 4
Leisure and Recreation

Leisure	Often	Sometimes	Rarely	Never
television	21	9	1	6
table games	2	15	8	12
active games	1	4	14	9
exercises	1	13	8	9
gardening	4	6	5	16
house chores	10	15	3	2
walks/hikes	8	5	9	9
needlework	2	6	4	19
craft or wood	1	0	0	30
collecting	1	2	1	27
draw/paint	0	5	5	21
listen to music	7	14	9	1
outdoor sport	0	1	11	19
books/magazines	5	20	3	3
photography	1	2	2	26
keeping a pet	7	5	2	17
chat with friend	19	7	4	1
cook/bake				

Recreation	Often	Sometimes	Rarely	Never
eat out	7	14	6	4
bowling	4	2	13	12
movies	2	11	7	11
sport events	0	5	6	21
shopping	4	14	6	7
museums				
church	9	10	2	10
concerts	0	7	9	15
parties	5	12	3	11
interest group	1	0	6	24
swimming	1	6	8	16
camping	0	2	4	25
live shows	0	0	4	27
senior center	2	6	4	19
travelogues	0	2	2	27
fairs/carnivals	2	7	9	13
amusement parks	3	5	8	15
speakers	0	2	5	24
visiting friends	3	5	11	12
going to a mall	2	9	9	11
taking a class	0	3	3	25

Participating Kennedy Seniors = 31

Kennedy Community Access 1986

Table 5
Cognitive Development

Mental Retardation Level		
(SDD)	Mild	10
	Moderate	19
	Severe	2

Communication	Near Average	Below Average
Expressive	23	8
Receptive	24	7
Intelligibility	20	11

Functional Academics	Independent	Some	Much help	None
read, sentence, program	9	6	4	12
read only survival words	12	6	8	5
write words	5	8	5	13
tell time	15	4	4	8
use money	7	6	11	7
count change	6	6	10	9
use calendar	12	9	6	4

Table 6
Use of Community Services

	Uses	Doesn't		Uses	Doesn't
County Board MR/DD	29	2	senior friends	0	31
residential services	16	15	medical services	2	29
M H Services	2	29	doctor	29	2
rehabilation	1	30	dentist	24	7
guardianship	1	30	medical equipment	1	30
transportation	7	24	speech therapy	0	31
church	4	27	occupational therapy	0	31
legal service	0	31	physical therapy	1	31
senior center	5	26	podiatrist	1	30
home meals	1	30	pharmacist	1	30
day care	2	29	other	4	27

Kennedy Companions for 31 participating Kennedy Seniors

Volunteer	18
Senior Friend	13

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DEVELOPMENTAL DISABILITIES PROGRAMS: BUDGET INFORMATION

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March 5, 1984

Updated
October 24, 1986

DEVELOPMENTAL DISABILITIES PROGRAMS: BUDGET INFORMATION

INTRODUCTION

The developmental disabilities programs provide a mechanism to plan and coordinate services and to protect the rights of persons with developmental disabilities. 1/ The definition of developmental disabilities includes those physical and/or mental impairments which are severe and chronic in nature and which result in a variety of substantial functional limitations. The developmental disabilities programs include State grants for planning and demonstration services, protection and advocacy services, special projects, and university affiliated interdisciplinary training for personnel serving the developmentally disabled.

For further information on the definition of developmental disability and the four program components see, The Developmental Disabilities Programs: Statutory Authority and Program Operations, Congressional Research Service (CRS) Report No. 84-196 EPW, November 8, 1984, by Mary F. Smith.

1/ Developmental Disabilities Assistance and Bill of Rights Act, P.L. 91-517, as amended.

TABLE 1. Authorizations and Appropriations for the Developmental Disabilities Programs
(in millions)

	Authorizations			Appropriations			
	FY 1985	FY 1986	FY 1987	FY 1985	FY 1986 P.L. 99-178	FY 1986 post-sequestration a/	FY 1987 P.L. 99-500
Grants to States (Sec. 131)	$50.25	$53.4	$56.5	$50.25	$53.4	51.1038	56.5
Protection and advocacy (Sec. 113)	13.75	14.6	15.5	13.75	14.6	13.9722	15.5
Special project grants (Sec. 145)	2.7	2.8	3.1	2.70	2.8	2.6796	2.5
University affiliated facilities (Sec. 123)	9.0	9.6	10.1	9.0	9.6	9.1872	9.187
TOTAL	$75.7	$80.4	$85.2	$75.7	$80.4	76.9428	83.687

a/ This column reflects reductions made under Gramm-Rudman-Hollings, the Balanced Budget and Emergency Deficit Control Act of 1985, as ratified by P.L. 99-366.

Recommendations
Relating to the
Reauthorization of the
Developmental Disabilities Assistance
and Bill of Rights Act

Consortium for Citizens with Developmental Disabilities

Task Force on Developmental Disabilities

Consortium for
Citizens with
Developmental
Disabilities

Susan Ames-Zierman 347-1234
Bill Jones 588-8252
Co-Chairs
Task Force on
Developmental Disabilities

INTRODUCTION

The Developmental Disabilities Assistance and Bill of Rights Act (Public Law 98-527) is scheduled for reauthorization during the first session of the 100th Congress. The following document represents the best thinking of members of the Consortium for Citizens with Developmental Disabilities Task Force on Developmental Disabilities, which consists of organizations concerned about services to people with developmental disabilities and contains recommendations to improve the effectiveness of the Developmental Disabilities Act.

In general, there is widespread satisfaction with the current law and the suggestions offered here are intended to fine-tune program operations and to enhance the effectiveness of the four programs authorized by the Act: the Basic State Grant Program, the Protection and Advocacy Systems, the University Affiliated Programs and Grants of National Significance/Special Projects.

Because this law is reviewed frequently, usually every three years, it is able to reflect the newest thinking in the developmental disabilities field and to continue to be on the cutting edge of improving the lives of people with developmental disabilities. The following recommendations aim not only to keep the programs current but to look to the future.

The organizations listed below endorse the recommendations presented in this document. While in a few instances there are varying views regarding how to solve particular problems, there is consensus regarding the substance of the issue areas themselves. Such views are reflected in notes following the recommendations for the convenience of the reader.

The CCDD acknowledges and appreciates the contributions made over the years by the Senate Subcommittee on the Handicapped and the House Subcommittee on Health which have improved the Developmental Disabilities Act. We look forward to working with Members of Congress during the up-coming reauthorization process. For further information, contact the co-chairs of the Developmental Disabilities Task Force indicated above.

Organizations Endorsing Recommendations Regarding
Reauthorization of the Developmental Disabilities Act

American Association of University Affiliated Programs
American Association on Mental Deficiency
American Foundation for the Blind
American Occupational Therapy Association
American Speech-Language-Hearing Association
American Physical Therapy Association
Association for Children and Adults with Learning Disabilities
Association for Retarded Citizens - U.S.
Child Welfare League
Epilepsy Foundation of America
Goodwill Industries of America
Mental Health Law Project
National Alliance for the Mentally Ill
National Association of Developmental Disabilities Councils
National Association of Private Residential Facilities for the Mentally Retarded
National Association of Private Schools for Exceptional Children
National Association of Protection and Advocacy Systems
National Association of State Mental Health Program Directors
National Association of State Mental Retardation Program Directors
National Head Injury Foundation
National Mental Health Association
National Recreation and Park Association
National Society for Children and Adults with Autism
The Association for Persons with Severe Handicaps
United Cerebral Palsy Associations, Inc.

RECOMMENDATIONS REGARDING THE REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

PROGRAMS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

PART A - GENERAL PROVISIONS

FINDINGS AND PURPOSES (Section 101)

ISSUE #1: During the 1984 reauthorization, the purposes of the Developmental Disabilities Act were refined and expanded to include increasing the independence, productivity and integration into the community of people with developmental disabilities. In the three years' experience operating under these expanded purposes, attention has been focused more clearly on the capabilities as well as needs of persons with developmental disabilities. Also, assistance to parents was greatly enhanced in PL 98-527 and new efforts in this arena have increased awareness of the importance of providing support to families in their desire to ensure that their family member will be able to live in the community throughout life. Therefore, to strengthen further the statement of purpose in the Act, the following is recommended.

> RECOMMENDATION: Include individual and family empowerment as one of the purposes of the Developmental Disabilities Act.

DEFINITIONS (Section 102)

> RECOMMENDATION: Add a new definition of the term "individual and family empowerment." Section 102 (11)

ISSUE #2: Several recommended changes in the State Plan and priority areas will require modifying definitions. The first is the titles of the priority areas.

> RECOMMENDATION: Modify three of the four terms used for federal priority areas as follows: community living (from alternative community living arrangements), employment (from employment related activities), and child development (from child development services). Part (11)(C) to become (12)(C)

ISSUE #3: Add the term and define "applied technology"

> RECOMMENDATION: The term "applied technology" means the systematic application of technology, engineering methodologies or scientific principles to meet the needs of and address the barriers confronted by individuals with developmental disabilities in areas including education, employment, supported employment, transportation, independent living and other community living arrangements. Section 102 (11)(H)

ISSUE #4: Because Developmental Disabilities Councils, Protection and Advocacy Systems and University Affiliated Programs have emphasized employment since 1984, there has been a broader investigation of the needs of adults with developmental disabilities in general, resulting in an awareness of the critical need to develop state-wide systems of case management. After studying the state of case management in the states, changes in its definition are suggested. Further, it needs to be made clear that the role of the DD Council in this priority area is to assist in the design and development of state-wide case management systems.

RECOMMENDATION: The term case management should be redefined as follows. Part 11(h)

Case management means a potentially life-long, goal-oriented process for coordination of the range of services needed by persons with developmental disabilities and their families. Case management is designed to ensure accessibility, continuity of care, and accountability and to ensure that the maximum potential of persons with developmental disabilities for independence, productivity, and integration into the community is attained. Case management, at a minimum, includes:

(a) outreach to identify eligible individuals;
(b) assessment and periodic reassessment to determine each individual's strengths, functional limitations and needs for specific services;
(c) participation in the development of a comprehensive individualized habilitation plan (IHP) as specified in Section 123;
(d) referral to and coordination of needed social, health, educational, support and other services as identified in the individualized habilitation plan;
(e) monitoring to ensure the delivery of appropriate services to the individual and his/her family and to determine progress in meeting goals and objectives specified in the IHP;
(f) advocacy to assist the individual in obtaining all services to which s/he is entitled and to effect changes in the service delivery system that will result in the individual's increased access to services. Section 102(11)(H) becomes Section 102(11)(I)

ISSUE #5: There are many activities which do not fit into the four federal priority areas and thus, if critical to the development of a comprehensive system of community services, must be described in terms of one or the other of the four priority areas or not done. The four federal priority areas are not mutually exclusive and by no means cover all possible activities needed on the state level for persons with developmental disabilities. Changes in the language authorizing a state optional priority during the last reauthorization have precluded using the state option as a vehicle for such activities in most states. For future policy purposes and for monitoring of the program, a full reinstatement and redefinition of the state priority area is needed. The states which have selected state priorities in the past have done so for very explicit reasons and their activities frequently indicate innovative activities which are helpful in planning future reauthorizations of the Act. Most states are now precluded from continuing those efforts. Several states have used their state option to stimulate, develop, maintain and/or train state-wide networks which can assist in implementing state plan objectives for policy change on the state and local levels. People in these networks, parents, professionals, people with disabilities and others, need to be trained and supported in policy and service issues. This capacity-building activity clearly supports the role of the DD Council as advocate described in the Act and represents the kind of activity intended by Congress to achieve the law's purposes.

People with developmental disabilities also have needs that are structural in nature, i.e., services or activities that must undergird a state's system, such as the development/coordination of rural services; consumer self-advocacy; public education/awareness activities regarding developmental disabilities; transportation services to enable people in residential programs to be able to work; socio-legal and protective services; prevention activities which go beyond early childhood-related issues; the support of technological developments for people with developmental disabilities; information and referral; outreach to unserved or underserved groups; community acceptance/organization; and other similar activities which go beyond the definition of any single federal priority area. These activities and others like them are essential to the development of a comprehensive system of services in our nation. Such innovative and successful activities do not "show up" clearly when reporting on the program and need to be monitored and shared to give direction for future federal policy and to enable states to learn from one another.

> RECOMMENDATION: The state optional priority area should be fully reinstated and its selection should be at the discretion of the states. It should not be conditional upon a demonstration that the federal priority areas are no longer needed, but upon a demonstration of the importance of such state priority activities to the development of a comprehensive array of services. A suggestion for a new definition of the optional state priority area is: "activities which effect positive change in specialized or generic services for persons with developmental disabilities, which are deemed essential by a State in achieving desired outcomes in its State Plan and/or which address two or more federal priority areas." Section 102(12)(A)(ii)

Issue #6: The Basic State Grant Program provides modest allocations to states for activities which build the capacity of the public and private sectors to provide services to people with developmental disabilities. These funds act as catalysts for state and local public and private dollars. These capacity-building activities should be reflected in the Act, emphasizing that Developmental Disabilities funds are for seeding, demonstrating and catalyzing permanent services financed under other authorities and through other means.

RECOMMENDATION: Language permitting the "provision of specialized services" in the priority areas should be deleted and the activity permitting "model service programs" should be modified to clarify that such programs are for demonstration purposes (i.e., model demonstration programs) Section 102(1)(B)(i) and (ii)

ISSUE #7: One of the most successful methods of DD Council advocacy for services is the dissemination of the results of studies of state policies which pose barriers to the independence, productivity and community integration of people with developmental disabilities. Best results in states frequently occur when the state legislature and/or Governor has been convinced by compelling facts that harmful laws should be changed or that new legislation is needed to meet identified needs. These activities need to be emphasized in the Act as service activities.

RECOMMENDATION: Language to include "policy analysis and educating policy makers" should be added to the definition of the term "service activities." Section 102(B)(viii).

Issue #8: Support to individuals and families is a vital component of successful community living. The definition of the community living priority area does not sufficiently specify individual and family support services.

RECOMMENDATION: Insert the words "individual and" before "family support services" in the definition of the federal priority area of community living. Section 102(D)

ISSUE #9: The Developmental Disabilities Programs were enacted to assure quality services for individuals who have severe and chronic disabilities. Since many state statutes still contain the "old" definition of developmental disabilities (listing categorical disabilities) the federal law needs to emphasize that Basic State Grant activities must be directed toward objectives, programs and resources for people who meet the requirements of the definition of developmental disabilities in Section 102(7)(A) through (E).

RECOMMENDATION: Committee report language should emphasize that federal law supercedes state statute with respect to the DD definition, that state plan activities should address the needs of those who meet the federal definition of developmental disabilities and DD Councils should be periodically required to review activities of subgrantees to ensure that the requirements of the federal definition are being met.

ISSUE #10: States are at various levels of sophistication in the design and provision of services to people with developmental disabilities, even though a great deal has been learned in recent years. To assist states, Congress should express its desire for programs funded under the Basic State Grant to be evaluated against best practices.

RECOMMENDATION: Committee report language should stress that activities funded under the Basic State Grant program are to be evaluated against professionally accepted best practices.

PART B - FEDERAL ASSISTANCE FOR PLANNING AND SERVICE ACTIVITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

STATE PLANS (Section 122)

ISSUE #1: Overwhelmingly DD Councils feel that the restriction on the number of federal priority areas a state may select is arbitrary and prevents states from clearly describing many cross-cutting and interagency initiatives in a precise way. Because the federal priority areas are very broadly defined and and inter-related and because the development of a comprehensive system of services may require the selection of all areas at any given time, the states need to be able to select up to the maximum number of federal priority areas. State Plans should continue to require that Councils indicate the percentage of funds allocated to each.

> RECOMMENDATION: Eliminate the restriction on the number of federal priority areas a state may select. Beginning in fiscal year 1988, the plan should be required to provide for at least one federal priority area and be permitted to provide for up to four federal priority areas. Section 122(b)4(B)(i)I. (See note 1)

Issue #2: States should be permitted to select a state optional priority area if it is deemed essential to the the development of a comprehensive array of services for people with developmental disabilities and/or if the activity addresses activities which overarch two or more of the federal priority areas. (See discussion under issue #5 on page 2 in the previous section.)

> RECOMMENDATION: Notwithstanding the requirements of subparagraph (B) at the option of the State, the State may provide for one or more additional activities addressing services for persons with developmental disabilities (as defined in Part A Section 102 (11) (A)(ii) which are deemed essential to the development of a comprehensive array of services and/or provision of two or more the federal priority area(s). The State plan must describe and provide an assurance regarding the need for such State optional priority or priorities. Section 122(b)(4)(B)(I)(iii).

Issue #3: Current law requires all states to select the priority area of employment in FY 1987 and thereafter. Even before this requirement, 43 Councils were actively pursuing employment, indicating that the new priority area rightly identified a need. Since all states have now embarked upon the employment priority area it is no longer necessary to require such selection. The mandatory selection of employment has served its purpose of getting states involved in the area. In addition, since capacity-building activities in all priority areas tend to be long-range, states can be expected to continue working in this area without a federal mandate to do so.

> RECOMMENDATION: Eliminate the requirement to select employment related activities as a federal priority area. Section 122(b)(4) (B)(ii). (See note 2)

Issue #4: In the 1984 reauthorization of the DD Act, a provision was added requiring that the state provide the DD Council a copy of any plans of correction for intermediate care facilities for persons with mental retardation and developmental disabilities (ICF/MR/DD) received by the state. No specific action was required, however, beyond receipt of the document(s).

> RECOMMENDATION: The DD Councils' Annual Report should describe actions taken by the State pursuant to any annual survey reports or plans of corrections for cited deficiencies prepared pursuant to section 1902(a)(31)(B) of the Social Security Act with respect to any intermediate care facilitaties for the mentally retarded/developmentally disabled in such State and should describe the response of the DD Council to such reports, plans and actions. (See note 3)

ISSUE #5: For more than a decade the most serious, recurring problem facing the DD Basic State Grant Program has been untoward control of State Planning Council actions, funding decisions and advocacy strategies by the designated state administering agency for the program. Previous attempts to correct such situations have been ineffectual.

In addition, the concept of administering agency/agencies as currently in the Act is antiquated, given the change in the role of Councils in recent years. There are no Councils which have more than one administering agency at this time. At present, because DD Councils (with the exception of California) are not designated "state agencies" in state statute, they are technically unable to administer Basic State Grant funds. Each state must have an entity authorized by state government to receive, disburse and account for federal funds. Attempts by administering agencies to control DD funds for purposes other than those intended by the Council have created many difficulties in many states. The Administration on Developmental Disabilities provided program guidelines regarding the organizational location of DD Councils in 1977, which has never been clarified in statute, thus permitting considerable interpretive latitude. The issuance states that "the Council should be organizationally located with appropriate stature and resources within the state system to effectively advocate for developmentally disabled persons (sic)...by having the Council located within (1) the immediate Office of the Governor, (2) the State Planning office, or (3) the immediate office of the head of the administering agency. In any case, however, the Council shall report directly to the Governor." DD Councils and the CCDD have discussed various methods for overcoming these serious problems and have concluded that since there is no single solution which will help all states, an incremental step can be taken to begin to address the issue.

> RECOMMENDATION: Clarify that there is a single state agency needed to administer the program and permit DD Councils to be their own administering agency, similar to the Early Intervention Councils authorized under the Education for Handicapped Children Amendments of 1986. Second, clarify that expenditures in support of the priority areas must be guided by the decisions of the DD Council. And third, reflect the 1977 policy issuance outlined above. (See note 4)

ISSUE #6: Demographic studies have shown that there is a need to address America's aging population. Services to elderly people who have developmental disabilities need to be planned and coordinated with services autnorized by the Older Americans Act.

> RECOMMENDATION: Add the aging plan (developed pursuant to the Older Americans Act) to the list of other state plans for federally assisted state programs to be described in the DD state plan. Section 122(2)(C)(i)

ISSUE #7: To address the state optional priority, the state should be required to assure that it is needed and should be required to provide a rationale in the State Plan.

> RECOMMENDATION: Add the following assurance to Section 122(b)(3): (G) in the event a State selects priority activities in addition to the federal priority areas, that such additional activities are essential to successful implementation of the State Plan.

ISSUE #8: Staff for the state Planning Council are usually employees of the state's civil service system. They provide support to the Council and, at the same time, are employed by a state agency that administers the program. This places Council staff in a position of "serving two masters" and conflicts occur between agency policy and Council advocacy efforts. For example, if the DD Council takes a policy position with which the agency disagrees, the Council staff director may be precluded from implementing that decision. This weakens the effectiveness of the DD Council in its role as advocate. In addition, Council staff have frequently been assigned responsibilities by the administering agency which are not directly related to the support of the Council and its decisions, in violation of Congressional intent and administration policy issuances. Because funds for the Basic State Grant program are limited, this further reduces the staff's capacity to carry out the mandates of the program. Congress has made clear in Conference Report No. 94-473 that the Council staff should have responsibilities only to the Council and not to the administering agency. The report further clarifies that instructions to and supervision of Council staff must take place directly between the Council and its staff. To ensure that Congressional intent is implemented, the law must contain a clear prohibition of such inappropriate interference with the activities of Council staff.

> RECOMMENDATION: Add statutory language which reflects the 1978 Conference Report and ADD policy issuances regarding personnel to the Developmental Disabilities Council, requiring that they be in such numbers and have such qualifications to enable the Council to carry out its duties under this title, that Council staff not be assigned duties by the administering agency, and that instructions to and supervision of Council staff must take place between the Council and its staff. Section 122(b)(3)(H). (See note 5)

ISSUE #9: While many people with developmental disabilities have mental retardation, there are other individuals with severe disabilities who have no cognitive impairment. Although all people with developmental disabilities have many needs in common, the latter group have special concerns which need to be addressed.

> RECOMMENDATION: The state plan should indicate what resources are available in the state for people with developmental disabilities who do not have mental retardation and ways in which the Basic State Grant program intends to address identified gaps in services. (See note 6)

STATE ALLOTMENTS (Section 125)

Issue #10: Minimum allotment states and territories have struggled with limited funds to provide core functions required of all DD Councils, regardless of the size of the state/territory. There is a need to increase the minimum allotment.

> RECOMMENDATION: In any case in which amounts appropriated under Section 130 for a fiscal year exceed $60,000,000, the allotment under paragraph (1) for such fiscal year
>
> (A) to each of American Samoa, Guam, the Virgin Islands and Commonwealth of the Northern Mariana Islands or the Trust Territory of the Pacific Islands may not be less than $200,000; and
>
> (B) to each of the several States, Puerto Rico, or the District of Columbia, may not be less than $350,000.
>
> (C) For any fiscal year in which an increase in appropriation for that year is greater than the Consumer Price Index percentage increase, the Secretary shall be permitted to increase the minimum allotment administratively. Section 125(a)(4)

AUTHORIZATION OF APPROPRIATIONS (Section 130)

ISSUE #11: The following appropriations levels are recommended.

> RECOMMENDATION: For allotments under section 125, there should be authorized to be appropriated $62,200,000 for fiscal year 1988, $69,900,000 for fiscal year 1989 and $77,400,000 for fiscal year 1990.

PART C - PROTECTION AND ADVOCACY OF INDIVIDUAL RIGHTS

PURPOSE (Section 141)

ISSUE #1: The purpose of the Protection and Advocacy System should closely reflect the overall purpose statement in the Act.

> RECOMMENDATION: Add after "of persons with developmental disabilities" the phrase "to assure that they receive the services necessary to enable them to achieve their maximum potential through increased independence, productivity and integration into the community."

SYSTEM REQUIRED (Section 142)

ISSUE #2: Minority persons who have developmental disabilities have been a priority for service for many Protection and Advocacy agencies. The Department of Health and Human Services has provided funds in the past for P&As to develop outreach programs for minority persons with developmental disabilities through demonstration grants from the Office of Civil Rights and the Administration on Developmental Disabilities.

> RECOMMENDATION: A specific focus to meet the needs of underserved minority persons needs to be added to the Act.

ISSUE #3: Protection and Advocacy agencies, because of insufficient resources, have not adequately addressed the needs of persons with developmental disabilities who become involved in the criminal justice system.

> RECOMMENDATION: A specific focus to address the needs of persons with developmental disabilities involved in the criminal justice system should be added to the Act.

ISSUE #4: The P&A programs have been heavily involved in the enforcement of P.L. 94-142, the Education for All Handicapped Children Act. P&As report 40% of their cases involved special education issues. This effort must be further enhanced.

> RECOMMENDATION: Reports from the Office of Special Education at the U.S. Department of Education and the state monitoring reports of local education agencies must be provided to the P&A systems.

ISSUE #5: The P&As must be able to advocate for persons with developmental disabilities before all appropriate governmental entities such as boards, commissioners, city and county councils and state legislatures.

> RECOMMENDATION: Language should be included in the P&A authority to make clear that the P&A systems may advocate before appropriate public bodies on behalf of people they serve.

ISSUE #6: Several P&As use subcontracts to achieve a full range of advocacy services throughout the state. From time to time, subcontractors will return unexpended funds in the next fiscal year which the P&A cannot use for recontracting of services. Use of these funds should be allowed with timelines on reobligation and liquidation.

> RECOMMENDATION: A carryover of 10% of the yearly allotment should be allowed to give flexibility in management of funds and to avoid problems of obligation of money.

> RECOMMENDATION: Funds which were obligated in the current fiscal year but are subsequently returned in the next fiscal year should be available for reobligation and should not be required to be returned to the federal government.

ISSUE #7: Protection and Advocacy Systems engage in a priority setting process at least every three years and many review priorities annually. Community input would enhance the process and assure accountability of the system.

> RECOMMENDATION: Provide for input by the disability community in the planning and priority setting activities of the Protection and Advocacy Systems.

ISSUE #8: Protection and Advocacy Systems, like any service provider, should be accountable to individuals whom they serve. At times clients are dissatisfied with the handling of their cases and should be afforded the opportunity to challenge the decision of the Protection and Advocacy System regarding their case. Recognition should be made, however, of the extensive P&A mandate and the limited resources available to carry out this mandate and the impact this limitation poses regarding responding to such complaints.

> RECOMMENDATION: Provide for a client grievance procedure within the P&A agency to assure that persons with developmental disabilities have full access to advocacy services.

ISSUE #9: Based on the continued depopulation of state institutions and nursing homes as well as the relocation of individuals within community living arrangements, a large number of individuals are being moved with no advocacy or legal representation.

> RECOMMENDATION: Language should be included to provide the Protection and Advocacy Systems standing and representation in all situations where an individual over the age of 18, who has no family or legal guardian other than the state or county (who have potential conflicts of interest), is being considered for a change in his/her living arrangement to assure that the proposed new arrangement is appropriate to the individual's needs and that the services needed are in place or will be in place prior to such a move.

AUTHORIZATION OF APPROPRIATIONS (Section 143)

ISSUE #10: The minimum allotments should be readjusted to enable P&As in all states to provide an adequate level of service.

RECOMMENDATION: The Commissioner of the Administration on Developmental Disabilities should have the option to raise minimums administratively in years in which an appropriation increase for that year is greater than the Consumer Price Index percentage increase.

RECOMMENDATION: The minimum allotment should be raised automatically to $250,000 when the appropriation reaches $20 million.

ISSUE #11: Based upon increased mandates for expanded services described above, the authorization levels for P&As need to be increased.

RECOMMENDATION: Authorization of appropriations for FY 1988 should be $25 million, for FY 1989, $28 million and for FY 1990, $31 million.

PART C- UNIVERSITY AFFILIATED PROGRAMS

ISSUE #1: The UAP network has not had the necessary federal funding resources to meet the training expectations of the developmental disabilities field. As such, UAPs have diversified in many areas, seeking funds from a variety of federal, private and state agencies in an effort to obtain the critical mass to address the training role. Present information suggests that this trend is growing steadily worse. The core funds provided by the Developmental Disabilities Act to the UAP network need to be increased.

> RECOMMENDATION: Authorization levels for the minimum allocation or core funding of full UAPs should be increased to $300,000 and satellite UAPs to $220,000.

ISSUE #2: There are currently 15 states (Hawaii, Alaska, Nevada, Idaho, Wyoming, North Dakota, Oklahoma, New Mexico, Arkansas, Illinois, Delaware, New Hampshire, Maine, Texas and Rhode Island) that do not have a DD-UAP. Consequently, these states suffer in at least two ways. First, there is no in-state mechanism to provide the specialized personnel preparation for the various programs that serve children and adults with developmental disabilities. Second, few - if any - programs in a state without a UAP can meet the interdisciplinary needs of "dually diagnosed" children (i.e., those youngsters with both mental retardation and some other disabling condition). In the vast majority of cases, community providers, hospitals, the State Title V Programs for Children with Special Needs (formally State Crippled Children's Services Programs) and other programs simply do not have the staff, resources and equipment necessary to provide effective services to these children.

> RECOMMENDATION: At minimum, each state should have one UAP. Congress should make available $30,000 for each of the 15 in FY 1988 for the conduct of simultaneous feasibility studies (currently required by ADD) to enable these states to have satellites or full UAP by FY 1989. There are currently seven satellite UAPs, many of which are ready to become comprehensive UAPs. Funds obligated for new satellites should be added to existing UAP appropriations and phased in over a two-year period. Therefore, no new programs should be created until the requirements of the appropriations trigger outlined above are met. (See Issue #6 below) Funds needed in FY 1988 total $450,000.

ISSUE #3: The demand for allied health professionals trained in the developmental disabilities field has increased, placing a substantial burden on an inadequate pool of skilled personnel. Specifically, many more trained specialists in a wide variety of fields are needed to develop the individual education and service plans (IEPs/ISPs) mandated by existing law and required for effective service delivery. There is a great need for personnel with interdisciplinary training, particularly for staff to provide services authorized by the new early intervention program in the Education of All Handicapped Children Amendments of 1986 (P.L.99-457). This program would assist states to develop and implement statewide, comprehensive, coordinated, multidisciplinary, interagency programs of early intervention services for handicapped infants and toddlers and their families (specifically infants from birth to three).

RECOMMENDATION: The authorization of $1 million to provide support for five to seven pilot development and implementation training projects (each approximately $150,000 to $200,000) through 1990. The tasks of each pilot training project will be to plan, design and implement an interdisciplinary training program to help prepare allied health professionals needed to provide early intervention services.

A standard application process administered by the Secretary should be used. A UAP prior to submitting its application, must inventory local community-level direct care and paraprofessional training programs to seek their guidance and input in the preparation of applications. Such applications would demonstrate that any UAP-provided training would be explicitly coordinated with these local programs.

ISSUE #4: There is increasing integration into the community of persons with developmental disabilities and, therefore, an expanding need for direct care personnel for community-based service programs. There has been a dramatic increase in the need for personnel with interdisciplinary training because of the overall expansion in badly needed community-based day and residential services to persons with developmental disabilities. Existing training programs are ill-funded and essentially ad hoc in nature. There is a need to focus a new training program to prepare hands-on, direct care personnel and paraprofessionals who are employed in community-based residential programs.

RECOMMENDATION: Authorize the demonstration and implementation of five to ten training programs for direct care workers and paraprofessionals at a level of $1 million for FY 1988, $1 million for FY 1989 and $1 million for FY 1990.

A standard application process administered by the Secretary should be used. A UAP, prior to submitting its application, must inventory local community-level direct care and paraprofessional training programs to seek their guidance and input into the preparation of the application. Any UAP provided training will be explicitly coordinated with these local programs. (See note 7)

ISSUE #5: Available data suggest that the number of elderly people with developmental disabilities is substantial and growing rapidly. Current national estimates indicate that there are over 200,000 individuals with severe disabilities who are 55 or older. Just 15 years from now that figure could realistically double. Our existing service and training systems are unprepared to address the needs of this burgeoning group. A major reason for the lack of appropriate services (or, in many cases no services at all) is the lack of trained personnel at all levels, from geriatricians to nutritionists.

RECOMMENDATION: Authorize 10 UAPs to provide cross-training in the developmental disabilities field and in the aging field for geriatricians, internists, nurses, social workers and other allied health professionals. Authorize appropriations of $1.167 million per year.

ISSUE #6: According to funding data published by Dr. David Braddock of the University of Illinois in a recent study entitled, "Federal Spending for Mental Retardation and Developmental Disabilities," the Administration is spending - in real terms - one million fewer dollars on UAPs today than it did at the inception of the program in 1972 ($4.25 million in FY 1972 compared with $3.345 million in adjusted dollars as of FY 1985). Moreover, the individual programmatic responsibilities and the number of persons served by UAPs (now over 75,000 children and adults nationwide) have also increased substantially over the last 15 years.

> RECOMMENDATION: For the UAP authority, authorization of appropriations should be $15.927 million in FY 1988; $19.387 million in FY 1989; and $20.267 million in FY 1990. The trigger for new programs to be funded is recommended at $19.387 million in FY 1989. In view of the expansion proposals discussed above, an appropriations trigger is needed to maintain existing programs. These recommended authorization levels encompass all UAP programmatic recommendations and initiatives contained in this section.

PART E - SPECIAL PROJECT GRANTS

ISSUE #1: For many years, advocacy organizations have been dissatisfied and disappointed with the overall results of Special Projects funded under this authority. The needs of the developmental disabilities community for nationally significant activities are greater now than ever and, as funds for Special Projects were reduced over time, less and less has been available for the kinds of activities which provide information enabling states and federal policy makers to base decisions on facts. This authority needs to be totally restructured and carefully monitored by Congress.

RECOMMENDATION: Re-title Part E to Nationwide Policy Initiatives to Improve Services to People with Developmental Disabilities.

PURPOSE (SECTION 161)

RECOMMENDATION: The purpose of Part E should be "to provide funds for grants and contracts for up to five years to public and/or non-profit private agencies for initiatives which have an impact on national policy to improve services to people with developmental disabilities through: (1) data collection and dissemination; (2) technical assistance; and (3) federal interagency initiatives.

GRANT/CONTRACT AUTHORITY (SECTION 162)

ISSUE #2: A major problem with the current program is that it does not fund on-going data collection activities needed to provide the nation and Congress with the information vital to policy decisions affecting people with developmental disabilities. In addition, many demonstration projects funded by Part E are inappropriate for federal funding and should, in fact, be demonstrated at the state and local levels. Such demonstrations should no longer be funded by this authority. Some of the most outstanding special projects in the past have been various policy analyses which provide needed data to enable states and the federal government to document problems and opportunities presented by state and federal policy.

In addition, the programs authorized by the Developmental Disabilites Act, the Basic State Grant Program (Councils and their Administering Agencies), Protection and Advocacy Agencies, and University Affiliated Programs have information regarding services to people with developmental disabilities that has not been collected and shared nationally. A database should be required which will be on-going, up-dated and widely available to groups, agencies and individuals. Such a database would significantly improve (1) overall program accountability (Congress and the administrative agencies could monitor the progress of all four program components to determine how well they are meeting their statutory objectives); (2) communication and sharing of information among state agencies, UAPs, DD Councils and P&As, reducing duplication of effort and receiving maximum benefit from limited resources; and (3) the ability of policy-makers to track current trends and adjust the service delivery systems. If sufficient funds are provided, the data base could collect and disseminate data from a broad range of additional programs and projects, including projects funded under this authority, forming the basis for programmatic initiatives across federal agencies. Such data collection, analysis, dissemination and data base development should be one of the major functions of this discretionary authority.

RECOMMENDATION: $1 million should be earmarked for the on-going collection of data to be used for policy analysis and dissemination on a nationwide scale regarding policies and services affecting persons with developmental disabilities, including but not limited to activities which (a) collect and disseminate data regarding federal and state funding of services for persons with developmental disabilities under various federal and state authorities and (b) collect and disseminate data regarding the activities and effectiveness of the DD Councils, Mental Retardation/Developmental Disabilities State Agencies, the Protection and Advocacy Systems, the University Affiliated Programs and the National Policy Initiatives authority.

ISSUE #3: The availability of on-going technical assistance to improve the effectiveness of the programs authorized by the DD Act is woefully lacking and desperately needed. As the regional HDS offices have consolidated from ten to four, and as staff of the Office of Human Development Services has been reduced, programmatic and management assistance has declined to almost nothing. An on-going technical assistance capability needs to be assured to share state information nationally and to provide specific assistance to improve the three programs at the state level. Technical assistance should be the second major function of this discretionary authority.

RECOMMENDATION: $400,000 should be earmarked for the on-going development and provision of training and technical assistance to Developmental Disabilities Planning Councils, Protection and Advocacy Systems, University Affiliated Programs and Developmental Disabilities State Agencies. (See note 8)

ISSUE #4: Finally, federal funds under this authority should reflect the capacity-building nature of the state programs and should be used as a catalyst for agencies outside of ADD to serve people with developmental disabilities under other authorities. Also, through such interagency activities, ADD will gain expertise in the wide range of federal/state programs which have an impact on people with developmental disabilities. Potential federal agencies with which cooperative projects could be rfunded include: the Social Security Administration, the Department of Housing and Urban Development, the Department of Labor, the Office of Special Education and Rehabilitative Services, the Health Care Financing Agency, and other divisions within the Office of Human Development Services, etc. Federal interagency initiatives should be the third major function of this discretionary authority.

RECOMMENDATION: $1 million should be earmarked for federal interagency initiatives which are nationally significant in increasing the capacity of states to serve people with developmental disabilities.

ISSUE #5: There is a need to provide information to (1) parents and people with disabilities regarding services that are available in their part of the country; (2) professionals regarding both service availability and consulting expertise in various organizations and/or in particular specialized areas; (3) professionals and consumers alike regarding model programs, publications and resource materials and ongoing research projects. A major thrust of a system design would be to coordinate and link already existing computerized information and referral systems in states and communities.

It is proposed that one to three studies be conducted to test the feasibility of the development of a nationwide information and referral system. The study or studies would examine currently operating local, state, regional and national systems in the various programmatic fields listed above to determine whether or how they could be coordinated and integrated into a national network. Should the study conclude that a coordinated I&R system of national scope would be possible, cost effective, meet state and local needs and increase access to services, the design phase would take place in the second year. In the third year, technical assistance would be provided to states and localities in the design, operation and national linkage of their own I&R systems.

> RECOMMENDATION: $250,000 should be earmarked in FY 1988 for the initial feasibility study, $250,000 in FY 1989 for the design phase and $250,000 in FY 1990 for technical assistance.

ISSUE #6: Since 1983, funds authorized under this Part have been co-mingled with funds authorized by other programs of the Office of Human Development Services which provide services to Native Americans, foster and adopted children, and the aging. Requests for proposals have focused on "cross-cutting" projects which address the common needs of combinations of these populations. Since the DD Special Projects Program is small, this dilution of the focus on issues addressing the specific needs of people with developmental disabilities should be prohibited. Opportunities for creative interagency initiatives have been proposed in Issue #4 above.

> RECOMMENDATION: Prohibit the inclusion of DD Special Projects funds in the Office of Human Development Coordinated Discretionary Fund.

ISSUE #7: The identification of issue areas in which to fund activities under this section needs to be opened to a public process whereby experts in the field, parents, and people with disabilities have an opportunity to provide input to the Administration on Developmental Disabilities regarding the most critical needs. While ADD should retain some discretion in the areas to be funded and exert stewardship of this program, particularly in the area of interagency initiatives, all too often the funding areas selected have been tangential, at best, to the greatest needs in the developmental disabilities field.

RECOMMENDATION: ADD should be required to solicit views from the field prior to the publication of the announcement of the priority areas selected for funding under this authority and should be further required to respond to the suggestions, indicating which were heeded, which were not, and why.

ISSUE #8: Authorization of appropriations levels should reflect activities described above.

RECOMMENDATION: Authorization levels for FY 1988, $2.65 million; for FY 1989, $2.78 million; and for 1990, $2.92 million.

SUMMARY TABLE OF RECOMMENDED AUTHORIZATION OF APPROPRIATIONS
DD ACT PROGRAMS
(in millions)

	FY 1988	FY 1989	FY 1990
BASIC STATE GRANT PROGRAM	62.2	69.9	77.4
PROTECTION AND ADVOCACY SYSTEMS	25.	28.	31.
UNIVERSITY AFFILIATED PROGRAMS	15.927	19.387	20.267
NATIONAL POLICY INITIATIVES	2.65	2.78	2.92
TOTAL	105.777	120.067	131.587

NOTES

(1) Part B, Issue #1. United Cerebral Palsy Associations, Inc. (UCPA) believes that Councils should not be permitted to expand the number of federal priority areas they may select. The current state plan priority setting mechanism provides a forced choice decision-making process to have the state focus its resources on only three priorities to assure maximum impact and effectiveness of limited resources. Increasing the allowable federal priorities to four may lead to a more political decision making process and to a reduction of the impact and effectiveness of the program. UCPA agrees with the next recommendation, however, permitting states to select a state priority in addition to three federal priority areas.

(2) Part B, Issue #3. UCPA and the Epilepsy Foundation of America (EFA) believe that the mandated selection of the federal employment priority area should be retained as one of the state's three federal priorities. The largest single "bottleneck" in almost every state system for persons with developmental disabilities is the so-called "aging out" problem for children leaving their entitlement to a free appropriate public education under P.L. 94-142, the Education for All Handicapped Children's Act of 1975, and waiting for adult services. Employment services must be continued to assure implementation of new adult strategies and options promoting greater integrated employment opportunities for adults with developmental disabilities.

(3) Part B, Issue #4. The Association for Persons with Severe Handicaps (TASH) agrees with the recommendation as stated and would like to add a requirement that the state DD Council should review and comment on all changes affecting people with developmental disabilities in the state Medicaid plan to prepare for anticipated reforms in the Medicaid program. While current law already requires Councils to annually review Medicaid plans, there are problems in implementation which should be corrected in report language.

(4) Part B, Issue #5. UCPA amd TASH agree that Councils should be permitted to be their own administering agencies but believe there is a major problem with the recommendation if it does not goes beyond that. More than half of the DD Councils are administered by agencies which provide or fund services to people with developmental disabilities and/or other categories of persons with disabilities, placing DD Councils in obvious conflict-of-interest situations. DD Councils must be able to make decisions in an environment free of conflict of interest and without any potential for reprisal by the administering agency which may well have different needs, statutory requirements and priorities. In further support of the above recommendation, UCPA also notes that at least 20 state agencies currently administering the DD Program have no statutory authority or responsibility to meet the needs of people with developmental disabilities other than mental retardation. (See ARC comments regarding note 6)

(5) Part B, Issue #8. The National Association of State Mental Retardation Program Directors (NASMRPD) and the National Association of State Mental Health Program Directors (NASMHPD) agree that Council staff should be accountable programmatically to the Council. However, if Congress chooses to include this existing regulatory requirement in the statute, it should be made clear that Council staff personnel are administratively accountable to the appointing authority. This modification can be accomplished by adding the phrase, "and are administratively responsible to the designated state administering agency."

(6) Part B, Issue #9. The Association for Retarded Citizens - U.S. (ARC), the American Association on Mental Deficiency (AAMD), the National Association of State Mental Retardation Program Directors (NASMRPD), and the National Association of State Mental Health Program Directors (NASMHPD) have serious concerns about the recommendation to require State Councils to begin to distinguish between mentally retarded and non-mentally retarded people with developmental disabilities for purposes of planning and funding programs. It is important to remember that the original purpose of the Act was to focus on functional needs of persons with severe disabilities originating in childhood who are generally denied access to other generic and specialized systems. Most individuals with developmental disabilities have mental retardation. The vast majority, if not mentally retarded, have similar needs. To separate these two groups is impractical, flies in the face of the very basis of the Act and will ultimately divide the DD constituencies at all levels. The above organizations believe that the law not should not be amended as recommended.

On the other hand, UCPA believes the recommendation does not go far enough and believes it can demonstrate a clear record of Basic State Grant funds being targeted almost exclusively to persons with mental retardation. This organization feels that people with cerebral palsy, epilepsy, autism, spina bifida, and others with substantial functional limitations without mental retardation are entitled to a fair portion of the efforts of this program. Therefore, UCPA recommends that one-third of the Basic State Grant funds be earmarked specifically for system issues and services to meet the specialized needs of individuals with developmental disabilities other than mental retardation.

Regarding earmarking, the vast majority of CCDD organizations strongly oppose specifying a percentage of these funds for any particular subgroup of people with developmental disabilities. A large portion of citizens with developmental disabilities have multiple handicaps. To attempt to single out some for services while excluding others based on the category of their disabilities is blatantly discriminatory and violates the very basis on which the DD Act was created, especially in view of the fact that the fundamental aim of the Act is to stimulate cross-cutting endeavors rather than to provide basic operating support for service programs. State Councils and the state planning process should remain the mechanisms for deciding service priorities and allocations. The federal government should not set arbitrary spending patterns for State Councils nor should it put one segment of the developmentally disabled community against any other. This would simply replicate many of the administering agency control problems currently experienced at the state level and would likely destroy or jeopardize the planning process and the highly beneficial cooperative arrangements between and among DD groups in the states.

(7) Part C, Issue #4. NASMRPD and NASMHPD wholeheartedly agree that more attention needs to be given to training para-professionals to work in community day and residential programs for persons with developmental disabilities. These organizations also agree that University Affiliated Programs can play a constructive role in this process. However, given the limited amount of funds that would be directed to this area, NASMRPD and NASMHPD believe that: (a) funds should be earmarked for those purposes under the Special Project authority (Part E) rather than the UAP authority, to permit states a wider range of choices in organizing a system for training community workers, and (b) the purposes for which such funds are made available should be limited to the assessment of existing training resources and unmet needs, the preparation of statewide plans for addressing current and future manpower needs in this area and the demonstration of new, improved methods of using and coordinating training resources statewide.

(8) Part E, Issue #3. NASMRPD AND NASMHPD agree that technical assistance is needed, but feel that the statutory aims of such assistance should be broadly conceived, rather than narrowly focused on the needs of DD Councils, UAPs and P&As. The field of developmental disabilities is in the midst of a period of dynamic change in which views of best methods of organizing and delivering services are being reconceptualized. Technical assistance is needed to help state and local policymakers and providers of services to integrate these new concepts into their day-to-day activities on behalf of persons with developmental disabilities. DD Councils, UAPs and P&As can play a critical facilitating role in this process, provided such technical assistance is not limited to the effectiveness of these programs or the types of advice and assistance that previously have been the purview of federal regional officials.

Senator HARKIN. In closing, let me just say that individuals with developmental disabilities have made tremendous progress in the last few years. For me personally, it is exciting to see these changes made over time.

I have a brother who happens to be deaf, and he is somewhat older than I am. I can remember when he went deaf when he was about nine years old, I guess, he had meningitis, and because we came from a small community, a rural area, and we had no financial resources, he was obviously taken out of the home and sent to the State school for the deaf, a boarding school where things were not very good in those days, not very good. In fact he still tells stories about how they used to beat him in the school, and how they taught them at the school for the deaf that they had four occupations—they could be printers, bakers, cobblers—and there is one other one that I am missing. Anyway, they decided my brother was going to be a baker, and so he was taught to be a baker. He did not want to be a baker any more than I wanted to be a baker. But that was it; they made him do that. And when they tried to express themselves that that was not what they wanted to do, there was physical punishment inflicted upon them.

So we have made great changes in the last few years. The focus on the Developmental Disabilities Act has changed, as people have testified, from human limitations to greater emphasis on human capabilities. So I am looking forward to the challenges we face in reauthorizing the Act to assure that it continue to facilitate significant improvements in the lives of people with developmental disabilities by increasing their independence and productivity and integration into the community. As I said at the beginning, I am rather new to the legislative and legal and technical aspects of this, although as I said, I have a great personal interest in it that I have had all my life. So I look forward to working with the community on these things. I know that there will be disagreements, but that is part and parcel of the legislative process. And I hope that working together and having the fine cooperation, as I have, of Senator Stafford, Senator Weicker and others who have preceded me in this and who, I am sure, know a lot more than I do about it, that we will obviously reauthorize the bill and make needed changes to keep pushing those barriers further and further.

So thank you all, and the Subcommittee will stand adjourned.

[Whereupon, at 4:45 p.m., the subcommittee was adjourned.]

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